



# **Challenge TB – Core Measurement Stigma**

## **Year 2 Quarterly Monitoring Report**

**October-December 2015**

**Submission date: February 4, 2016**

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## 1. Quarterly Overview

|                    |                                  |
|--------------------|----------------------------------|
| Country            | Core project measurement: Stigma |
| Lead Partner       | KNCV                             |
| Other partners     | MSH                              |
| Workplan timeframe | July 2015 – September 2016       |
| Reporting period   | October - December 2015          |

### Summary progress report:

This is the first quarter since the approval of the Core Measurement- Stigma project by the donor. Activities that have taken place are both administrative and technical in nature.

#### Administrative:

The major administrative achievement of this quarter is the development of the two sub-agreements between KNCV and two research institutions (KIT Amsterdam and University of Antwerp), which have subsequently been approved and contracts signed.

University of Antwerp will support systematic literature review of strategies to reduce TB stigma.

And KIT Amsterdam will provide technical expertise on two parts of the project:

- Correlates of anticipated TB stigma in the general population
- Correlates of enacted TB stigma in health care settings.

#### Technical:

There are seven aspects of the core project, and technical progress in each area is summarized in order.

1. Prevalence Survey Review
2. Assess distribution and correlates of anticipated stigma in the general population
3. Assess the distribution and correlates of enacted stigma in health care settings
4. Assess robustness of existing TB stigma measures
5. Systematic literature review of stigma reduction strategies (Map what works)
6. Convene expert meetings
7. Prepare protocol for piloting and Baseline Stigma Measurement

### 1. Prevalence Survey Review

In 2015, Bill and Melinda Gates Foundation and USAID undertook an analysis of the role of prevalence surveys in TB control. KNCV Eveline Klinkenberg provided expert support to this endeavor, having participated in multiple prevalence survey efforts. Following a planning meeting in Paris, three country visits of the assessment were conducted in October (only one of which (Cambodia) was supported through CTB funds).

A desk review and discussions with NTP managers and other key stakeholders were conducted. The preliminary findings were summarized and presented in Cape Town in a special symposium on December 1st which was well received. In December, the consultant spent the rest of the time finalizing the first draft of the report which was submitted to USAID for review and comment.

In addition, through this project, Dr. Alaine Nyaruhirira, Senior Laboratory Technical Adviser, MSH was identified and approached by USAID to become a member of the evaluating team. Dr. Alaine's specific activities were to conduct desk review and site visits to Ghana and report on the same review and synthesize information on laboratory issues collected from all other 16 countries and contribute to the overall report. The field visit in Ghana was completed from October 18 - 24, 2015. The assessment findings were presented at the 46th International Union Conference in Cape Town in a special session.

The final report based on the desk review of 16 National Prevalence Survey reports and peer review papers published is in the writing process and is expected to be submitted to USAID, WHO and PMU at the end of January 2016.

## **2. Assess distribution and correlates of anticipated stigma in the general population**

An RFA was published for the secondary data analysis of DHS data on anticipated stigma (the TB disclosure question) and there was 1 applicant (KIT). Most applications to ORC Marco for data access were approved and data were downloaded and pre-processed.

- 3.** During this reporting period (October – December 2015), household, female, and male disaggregated data were appended by country for the selected 19 DHS study surveys. Variables were recoded and databases appended using Stata SE Version 13.1, in accordance the DHS database guidelines available online. The majority of the appended country-specific datasets were provided to KIT in November. However, there is an outstanding dataset composed of data from the following countries (Bangladesh 2004 <sup>(2)</sup>, Cambodia 2005, Ethiopia 2005, Ethiopia 2011, Haiti 2005-06, India 1992-93 <sup>(8)</sup>, India 1998-99, India 2005-06, Kazakhstan 1999, Kenya 2008-09, Kenya 2014, Kyrgyz Republic 2012, Lesotho 2004, Lesotho 2009, Liberia 2007, Malawi 2010 <sup>(10)</sup>, Moldova 2005, Namibia 2006-07 <sup>(14)</sup>, Namibia 2013 <sup>(12)</sup>, Nigeria 2008, Philippines 1998 <sup>(18)</sup>, Philippines 2003, Philippines 2008, Philippines 2013, South Africa 1998, South Africa 2003, Swaziland 2006-07, Tajikistan 2012, Tanzania 2007-08, Timor-Leste 2009-10, Turkmenistan 2000, Uganda 2000-01, Uganda 2004-05, Uganda 2006, Ukraine 2007, Uzbekistan 2002 <sup>(21)</sup>, Zambia 2007 <sup>(22)</sup>, Zambia 2013-14, Zimbabwe 2005-06) that still needs to be generated. Additional time is needed to complete this activity, and cost savings from other activities will be used to complete the dataset by the end of next quarter **Assess the distribution and correlates of enacted stigma in health care settings**

An RFA was published for the secondary data analysis of health care worker discrimination in African health facilities. There was 1 applicant (KIT). Most applications to ORC Marco for data access were approved and data were downloaded and pre-processed. Once the data became available, it became clear that some analyses would be impossible or unwise:

- The SPA survey analysis using direct HIV Qs – the use of these Qs have been discredited
- The analyses comparing community vs healthcare facility PLHIV discrimination – this strays from our TB mandate
- The GIS analysis for Tanzania and Rwanda – these data do not exist

KNCV proposed to replace these analyses with 2 new ideas:

- 1) Exploration of correlates of reporting (ie. denouncing) PLHIV discrimination
- 2) Exploration of correlates of asking caregivers about TB in the family (use of sick child observation) – this would only be possible in Kenya

KNCV ran into technical challenges with the merging of certain country's service provision assessment data because each data set has a unique structure and requires unique syntax. This results in a delay in sending 2 out of 4 datasets to KIT. Namibia, Kenya, and Tanzania were provided, but Rwanda is still outstanding. The data pre-processing workload was underestimated, and so there was insufficient LOE to complete this task. Therefore a graduate student will be identified to provide the remaining pre-processing work.

## **4. Assess robustness of existing TB stigma measures**

The collection of (the proliferation of) TB stigma scales has been challenging due to the fact that most are in the form of final reports of consultancies from GFATM and do not end up being published. We are using creative means to acquire them. KNCV initiated discussions with University of Vanderbilt epidemiologist Dr. Aaron Kipp, author of 4 papers on the Van Rie Stigma scale, to solicit his participation in the scale verification exercise.

## **5. Systematic literature review of stigma reduction strategies (Map what works)**

An RFA was published and there were 2 applicants. Both highly qualified and thus a process of independent review was undertaken and the contract was successfully awarded to U. Antwerp.

The protocol, data collection tools, and data entry templates were finalized for the systematic literature review by University of Antwerp in December. This systematic literature review process took longer and required more KNCV support than anticipated due to lack of timely supervision of graduate students by senior staff at University of Antwerp. Travel and illness precluded timely supervision. The Protocol received several rounds of inputs from the Head of the Evidence Unit, the Technical Unit, new Epidemiologist Alice Zwerling, and Epidemiologist Annelies Van Rie. See Appendix 3.

## **6. Convene expert meetings**

The main question and objectives of the TB Stigma Measurement meeting were defined (See Appendix 4).

Interest in the planned TB stigma meeting has been very high – with prominent stigma measurement experts such as Wim van Brakel, Ernesto Jaramillo, Annelies Van Rie, Edwin Wouters, Caroline Masquellier, and others anxious to have the expert meeting. The project is experiencing challenges in managing the expanding demand from stakeholders to attend the meeting and reconciling it with the limited resources to cover travel.

Many persons are contacting KNCV wishing to showcase their stigma measures, but none of them has been validated and many are just slight modifications of existing HIV stigma scales. In the absence of evidence of utility of such measures, it is very difficult to discern whether or not to use them.

The expert meeting originally scheduled for February 11-12 will be postponed due to the unavailability of Professor Wouters from the University of Antwerp. His participation is essential because his stigma measurement tool is the only one that has had any validated for measuring TB stigma among health care workers.

## **7. Prepare protocol for piloting and Baseline Stigma Measurement**

A mission to Lagos, Nigeria in early January was leveraged to explore with the State TB Program Officer, Dr. Razzaq, the program's interest in measuring TB stigma in public facilities that refuse to offer TB services as well as facilities that currently offer them. Dr. Razzaq was extremely supportive and has identified stigma as a significant barrier to the location of TB services in ART clinics, secondary level facilities. He noted that he had recently had several Xpert machines rejected from sites due to pervasive stigma, so he was keen to participate in any intervention to address TB stigma.

### **Technical/administrative challenges and actions to overcome them:**

The core project is progressing well. As anticipated in the approved work plan, there are data pre-processing challenges. In some instances, the LOE for specific tasks has proven inadequate and in others there is extra LOE, so some subtle adjustments are planned. Challenges with data pre-processing need to be addressed in the short term to preclude a delay in the analyses. To address these challenges we will move funds from other areas to try to cover the core deliverables. In we have developed a TOR to hire the Junior Researcher to expedite the progress on the Stigma meeting, the validation of scales, the data extraction for KIT, and to provide support to on the literature review. This should go a long way to picking up the pace of the project.

### **Collaboration**

In early January, a telephone meeting was held with U. Antwerp to developed mutual expectations regarding the quality and the timeliness of study outputs. An agreement to improve the quality of supervision of students was reached, and evidence of improved quality of work has been observed in recent weeks.

**Focus**

To manage the high level of interest in attending the meeting, it is important to stress that this meeting is for measurement of TB stigma, not a broad meeting for people interested in stigma. We will submit a symposium to the Union so that the papers can be shared with a wider audience at a later date.

**Validity of the disclosure question as a proxy measure of TB stigma**

A critical assumption underlying the exploratory analysis in phase 1 of this core project is that the question "If a member of your family got infected with tuberculosis would you want it to remain a secret or not?" is a valid measure of TB stigma. To our knowledge, the disclosure question has never been compared against validated stigma scales. In the HIV field, the use of disclosure as a proxy for stigma is contested. In discussions with stigma experts, it has become clear that the project needs to take additional steps to explore whether disclosure is a proxy for TB stigma or not. Otherwise the DHS analysis may seem trivial.

The best way to explore the validity of this proxy inexpensively, quickly, correctly before the expert meeting is held is unclear. In the absence of both time and money, there are only a few existing accessible datasets that could contribute to addressing this question. A dataset would need to have the TB disclosure question as well as other TB stigma questions (preferably validated ones). Another less favorable alternative would be to attempt to compare the performance of a validated stigma scale and the single disclosure question on two groups with similar characteristics (e.g. age, sex, geography, year). We will reach out to scholars who may have these data and be willing or able to analyze them without resources over the next few months.

## 2. Year 2 activity progress

| Sub-objective 1. Enabling environment  |            |  |  |  |                               |                                  |  |   |
|--|------------|--|--|--|-------------------------------|----------------------------------|--|---|
| Planned Key Activities for the Current Year  | Activity # | Planned Milestones                                   |  |  |                               | Milestone status                 | Milestone met? (Met, partially, not met) | Remarks (reason for not meeting milestone, actions to address challenges, etc.)   |
|  |            | Oct-Dec 2015   | Jan-Mar 2016   | Apr-Jun 2016   | Year end                      | Oct-Dec 2015                     |  |   |
| Assess distribution and correlates of anticipated stigma in the general population | 1.2.1      | Agree on Statistical Analysis plan, compile datasets | Presentation of preliminary findings, First draft report | Final Draft Report                                       |                               | n/a                              | Partially met                            | Long delay in contracting long time partners due to new USAID regulations. KNCV still to compile ecological data for 187 countries. |
| Assess the distribution and correlates of enacted stigma in health care settings   | 1.2.2      | Agree on Analysis plan, compile datasets             | Presentation of preliminary findings                     | Final Draft Report                                       |                               |                                  | Partially met                            | KNCV still to send Rwanda data sets   |
| Assess robustness of existing TB stigma measures                                   | 1.2.3      | Compile copies of all measures/tools                 | Presentation of preliminary findings                     | Report summarizing what is known about utility, validity |                               |                                  | Partially met                            | Some of the TB stigma scales have been obtained, but some authors have not provided translations or full details                    |
| Systematic liter review Map what works   | 1.2.4      | Finalize Protocol,                                   | Preliminary findings, presentation                       | Systematic literature review                             |                               | Protocol, dataset, interventions | Met                                      |   |
| Convene expert meetings  | 1.2.5      |  | Hold meeting   | Consensus recommendations,                               | TB stigma research agenda     |                                  | N/A                                      |   |
| Prepare protocol for piloting and Baseline Stigma Measurement                      | 1.2.6      |  |  |  | Baseline Report on tool pilot |                                  | N/A                                      |   |

### 3. Challenge TB-supported international visits (technical and management-related trips)

| #   | Partner | Name of consultant                    | Planned quarter |     |     |     | Specific mission objectives   | Status (cancelled, pending, completed) | Dates completed                                 | Duration of visit (# of days) | Additional Remarks (Optional)                                       |
|---|---------|---------------------------------------|-----------------|-----|-----|-----|---|--|---|-------------------------------|---|
|   |         |                                       | Q 1             | Q 2 | Q 3 | Q 4 |   |  |   |                               |   |
| 1   | KNCV    | Eveline Klinkenberg                   | Q 1             |     |     |     | Site visit to a country that has conducted two TB prevalence surveys as part of the USAID/Gates lead Global TB prevalence survey - Cambodia | Complete                               | 4 <sup>th</sup> -11 <sup>th</sup> Oct' 15       | 7                             | Finalization of the reports are currently underway                  |
| 2   | KNCV    | Eveline Klinkenberg                   |                 | Q 2 |     |     | Preliminary findings were summarized and presented in Cape Town during the Union conference in Cape Town South Africa                       | Complete                               | 30 <sup>th</sup> Nov- 2 <sup>nd</sup> Dec' 15   | 3                             |   |
| 3   | KNCV    | Ellen Mitchell                        | Q 1             |     |     |     | Discuss stigma project with U Antwerp and KIT in Antwerp and Amsterdam  | Complete                               | November  | 1                             | Discussions fruitful  |
| 4   | KNCV    | Ellen Mitchell                        |                 | Q 2 |     |     |   | Pending                                |   | 4                             | Preparations for the experts meeting                                |
| 5   | KNCV    | Ellen Mitchell/<br>Research Assistant |                 |     |     | Q3  |   | Pending                                |   | 7                             | Travel costs for 1 mission visit to the field by 2 persons- Nigeria |
| 7   | MSH     | TBD                                   | Q 1             | Q 2 |     |     | Conduct desk review and site visit to Ghana   | Complete                               | October 18 <sup>th</sup> – 24 <sup>th</sup> '15 | 6                             | Finalization of the reports are currently underway                  |
| Total number of visits conducted (cumulative for fiscal year) |         |                                       |                 |     |     |     |   | 4                                      |   |                               |   |
| Total number of visits planned in approved work plan          |         |                                       |                 |     |     |     |   | 7                                      |   |                               |   |
| Percent of planned international consultant visits conducted  |         |                                       |                 |     |     |     |   | 57%                                    |   |                               |   |





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## *Core Measurement Stigma*

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### **KIT proposal**

### **for support to the Challenge TB APA1 Work Plan for Core Measurement Stigma**

*Correlates of Anticipated TB Stigma in the General Population*

**October 2015**

Sandra Alba, Mirjam Bakker, Masja Straetemans

KIT, Royal Tropical Institute

Amsterdam

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# 1. Analysis plan

## 1.1 Data collection and data management

In conjunction with KNCV Senior Epidemiologist we will select surveys from priority countries that were conducted within the last 15 years that employ TB questions in general populations. Appendix 1 in the request for proposal contains a list of 42 DHS conducted in 28 countries since 1992; 27 of these DHS surveys have been conducted since 2005 in 22 countries. Selection criteria may e.g. include selecting the most recent survey if multiple surveys of one country have been identified. It can also be decided to select eligible surveys after exploratory data analyses if e.g. surveys have many missing data.

We propose that survey selection and compilation of the dataset including all survey data be performed by skilled Data Management services facilitated by KNCV Tuberculosis Foundation. In this proposal we assume that we are provided with one clean dataset combining the data of all selected DHS including accompanying metadata (e.g. dataset specifications, codebooks or dictionaries). However, if this will not be possible due to availability of the Data Management services, we could do this task as well, but that will have consequences for the realistic time line and budget of this proposal.

## 1.2 Operationalization of main dependent and independent variables

### 1.2.1 Anticipated TB stigma

Anticipated stigma (felt stigma, perceived stigma) refers to a stigmatized person's fear or anticipation of discrimination and rejection.<sup>1</sup> The presence of anticipated TB stigma will be operationalized as those individuals who have indicated that they have heard of an illness called Tuberculosis or TB and answered 'yes' to the following question in the DHS: "If a family member got tuberculosis would you want to remain it a secret?". Individuals who answered "no" or "don't know/not sure/depends" will be considered as having no TB stigma.

Hypothetical secrecy questions are often referred to as "disclosure questions" in the literature. There is a robust debate about whether disclosure of HIV status is a proxy for anticipated HIV stigma or not. This debate has yet to occur for TB stigma.

### 1.2.2 Socio-economic status, TB and HIV knowledge,

In DHS wealth indexes have been constructed as a measure for socio-economic status (SES) by principal component analyses (PCA). Potential asset variables collected in the DHS household questionnaires include e.g. durable asset ownership, access to utilities and infrastructure (e.g. sanitation facility and source of water), and housing characteristics (e.g. number of rooms for sleeping and building material). Based on the DHS wealth index households have been categorized into quantiles. After exploration of the available datasets we will be able to either use the Wealth Index variables as already calculated<sup>2</sup> or construct the wealth index by PCA.<sup>3</sup>

The two DHS questions related to TB knowledge are 1) 'How does tuberculosis spread from one person to another?' and 2) 'Can tuberculosis be treated?'. For our analyses, the response to the first question 'Through the air when coughing or sneezing' will be considered as correct knowledge on TB transmission. The other options (which may differ between countries) will be considered as misconceptions. A new variable will be created to indicate correct knowledge on TB transmission following the approach as described by Sreeramareddy *et al*<sup>4</sup>. The DHS also includes several questions on HIV knowledge including knowledge on HIV prevention methods, knowledge of prevention of mother-to-child transmission of HIV. One or more variables indicating adequate HIV knowledge will be constructed after Exploratory data analysis (EDA). The operationalization of TB and HIV knowledge will be clearly defined in the analyses protocol.

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<sup>1</sup> Swendeman D. et al. Predictors of HIV-related Stigma among Young People Living with HIV. *Health Psychol.* 2006 Jul; 25(4): 501-509

<sup>2</sup> <http://dhsprogram.com/topics/wealth-index/Wealth-Index-Construction.cfm>

<sup>3</sup> Vyas S., Kumaranayake L. Constructing socio-economic status indices: how to use principal component analysis. *Health Policy Plan.* (2006) 21 (6):459-468.

<sup>4</sup> CT Sreeramareddy, HNHK Kumar, JT Arokiasamy. Prevalence of self-reported tuberculosis, knowledge about tuberculosis transmission and its determinants among adults in India: results from a nation-wide cross-sectional household survey. *BMC Infectious Diseases* 2013, **13**:16

### 1.2.3 Health Care Seeking Behavior

DHS includes a number of questions on health seeking behavior related to e.g. seeking advice or treatment when a child was sick and if yes where; antenatal care questions; where to go for HIV testing and injections for any reason. To answer policy question 6 we propose to focus on the question being asked in the female DHS related to seeking advice or treatment for the illness with a cough at any in the last 2 weeks.

## 1.3 Rapid literature search

To assess which socio-demographic variables are correlated with TB stigma we will first conduct a rapid literature search in Pubmed identifying systematic reviews focusing on socio-demographic correlates of (TB) stigma. This knowledge will be useful for deciding a priori which socio-demographic factors are relevant to include in the model, but will also provide insight into relevant socio-demographic variables we might not be able to include because the data might not be available in the DHS.

## 1.4 Exploratory phase

EDA will be conducted to provide a narrative overview of data available from the dataset. We will summarize the data numerically and graphically, identify missing values and determine the extent of missingness and choose course of action if required. In this step we will also explore possible variable transformation. This phase will lead to a detailed data analysis plan which will be developed and discussed with the KNCV Senior Epidemiologist prior to the start of the analyses phase.

## 1.5 Analyses phase

To answer the 5 policy questions as defined in the request for proposal we propose to perform explanatory analyses to capture associations between the independent variables and anticipated TB stigma.<sup>5</sup>

### 1.5.1 Ecological modelling (policy questions 3 and 4)

To assess the variability in anticipated TB stigma between countries and within countries we will analyze and present the proportion of individuals with TB stigma by maximum two administrative levels: country level (admin0); state/province/region level (admin1). For admin0 we aim to present the variability in TB stigma not only in tables, but also visualize by using maps for those countries for which the shape-files related to the DHS surveys are freely accessible from the website of the DHS program.<sup>6</sup> Country level univariate and multivariate linear regression analyses will be conducted to assess the correlates of variability in TB stigma among countries including the role of MDR-TB estimated incidence, HIV and other co-morbidities as potential explanation of inter-country variation in general population attitudes toward TB. We will select additional relevant characteristics from the Global Health Repository<sup>7</sup> and/or World Bank<sup>8</sup> to assess if specific country characteristics are associated with widespread TB stigma. We need to be aware that these data are only available on national level.

### 1.5.2 Univariate logistic multi-level regression analyses (policy questions 1,2)

To assess the magnitude of the association between the independent variables socio-demographic assets (a. gender, b. age., c. socio-economic status., d. religion. e. urban/rural f. education), TB and HIV knowledge, and the dependent variable reflecting anticipated TB stigma (disclosure of family member's TB DX), we will perform, based on individual data, univariate multi-level logistic regression, including random effect for country and accounting for weighting implicit to survey structure.

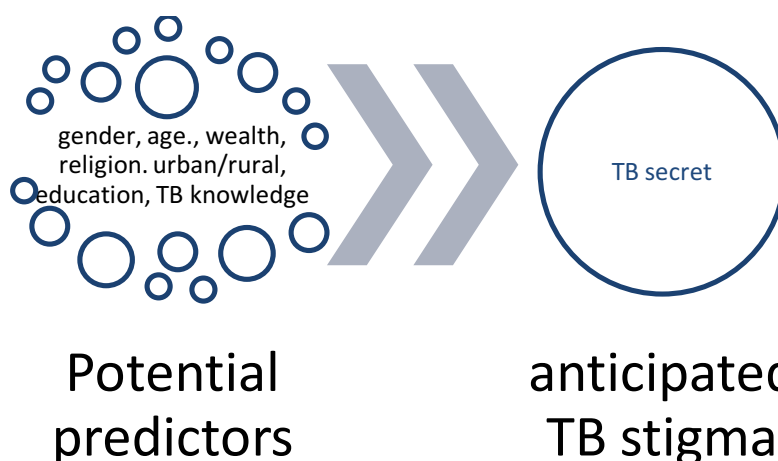
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<sup>5</sup> Shmueli G. To Explain or to Predict? Statistical Science 2010, Vol 25. No3, 289-310.

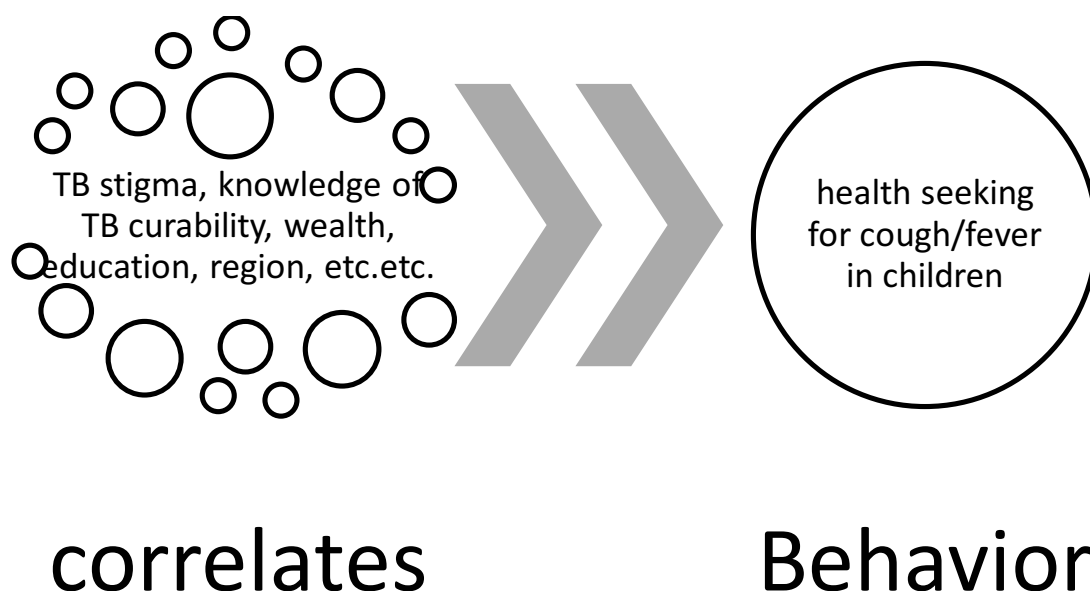
<sup>6</sup> <http://dhsprogram.com>

<sup>7</sup> <http://apps.who.int/gho/data/view.main>

<sup>8</sup> <http://data.worldbank.org/>



One of the most important questions for researchers to understand is the potential implications of TB stigma for health care seeking. There is a debate as to whether anticipated stigma reduces or accelerates care seeking. DHS data permit the exploration of this topic.



#### 1.5.3 Multivariate logistic multi-level regression analyses (policy questions 1,2)

Variables found to be associated with anticipated stigma in the univariate analyses will be used to build the multivariate multi-level logistic model including random effect for country and accounting for weighting implicit to survey structure.

#### 1.5.4. Analysing confounding patterns (policy question 2 )

The influence of potential confounding variables ( gender, age, SES, religion, urban/rural) in the association between the independent variables TB knowledge, HIV knowledge, and dependent variable anticipated TB stigma will be studied in more depth for those independent variables that were statistically significant in the univariate analyses (1.3.2). This will be done by adding potential confounders (those statistically significant in 1.3.2) one by one to the univariate models forcing the main independent variables in the model and observing the effect of the potential confounder on the association. Effect modification will also be assessed for plausible mechanisms.

### 1.5.5 Study the change in level of TB stigma over time (policy question 5)

There are nine countries with repeat DHS survey containing the TB module.<sup>9</sup> Most countries have only 2 time points, thus we may only be able to perform a descriptive trend analysis of TB stigma.

### 1.5.6. Univariate and multivariate multi-level regression analyses (policy question 6)

To study the association between anticipated stigma and healthcare seeking behavior univariate and multivariate analyses will be conducted on a similar approach as described above, while considering health care seeking behavior as independent variable.

## 2. Experts

We propose a strong team comprising of three PhD level scientists including a medical statistician, TB epidemiologist and an epidemiologist / geographic information expert.

**Sandra Alba, MSc, PhD**, is a medical statistician/epidemiologist at KIT. She obtained an MSc in Medical Statistics at the London School of Hygiene and Tropical Medicine in 2006, and soon after joined the Swiss Tropical and Public Health Institute for a PhD project. She contributed to the epidemiological design, designing data collection tools, coordinating fieldwork as well as data analyses and reporting of an evaluation study of a program aimed at improving and understanding access to malaria treatment in rural Tanzania. Data used for the evaluation consisted of cross-sectional community surveys as well as secondary analysis of demographic surveillance systems (DSS) and health management and information systems (HMIS) data. After completing her PhD in 2010, she spent two years working as a clinical trial statistician in a Contract Research Organisation based in Switzerland. Through this experience she developed expertise in analysing and reporting clinical trial data. During this time she taught various courses on clinical trial statistics for professionals of the pharmaceutical industry, and participated in the teaching of a module on Data Analysis in Epidemiology for the MSc course in Epidemiology of the Swiss TPH. At the end of 2012 she joined the KIT as a medical statistician/ epidemiologist, where she continues to be involved in epidemiological studies and evaluations of health interventions for the control of infectious diseases both in Europe and Africa. Her responsibilities further include teaching statistical and epidemiological methods to post-graduate students as well as supervising MSc students

**Mirjam Bakker, Ph.D.**, senior epidemiologist, is coordinator of a small group of epidemiologists/geographic information system (GIS) experts at KIT. Specialized in epidemiology of infectious diseases, she has extensive experience in the use of GIS in disease control, in operational/field research of tuberculosis (TB) and HIV care and prevention and in monitoring and evaluating TB case finding activities. She has been involved in several large epidemiological field studies in, among others, Indonesia, Rwanda and Malawi. She contributed to the epidemiological design, data collection, data-entry, data analyses, and reporting and developed specific expertise in the use of GIS linking spatial, demographic and health data to study transmission patterns and disease clustering. She was responsible for developing the course "Using GIS in disease control programmes", which she teaches on a yearly basis, furthermore she gave several GIS workshops. From the start in 2010 she was involved in the external monitoring and evaluation of the TB REACH initiative of the Stop TB Partnership. She was engaged in the development of the M&E framework and responsible for the overall compilation of results of over 100 projects. She supervises M.Sc. and Ph.D. students and is proficient in using STATA, ArcGIS and QGIS.

**Masja Straetemans, PhD** is a senior epidemiologist KIT. She obtained a Master of Science (MSc) in Environmental Health Sciences and a PhD in Epidemiology. She has over fifteen years of experience in epidemiological research at the university of Nijmegen (the Netherlands), the Centre for Disease Control and Prevention (USA), the Robert Koch Institute (Germany), the European Centre for Disease Prevention and Control (Sweden) and KNCV Tuberculosis Foundation (the Netherlands). She has been involved in study design, study implementation, data analyses and

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<sup>9</sup> Ethiopia 2005, Ethiopia 2011, India 1992-93 <sup>(8)</sup>, India 1998-99, India 2005-06, India 2014-15, Kenya 2008-09, Kenya 2014, Lesotho 2004, Lesotho 2009, Namibia 2006-07 <sup>(14)</sup>, Namibia 2013 <sup>(12)</sup>, Philippines 1998 <sup>(18)</sup>, Philippines 2003, Philippines 2008, Philippines 2013, South Africa 1998, South Africa 2003, Uganda 2000-01, Uganda 2004-05, Uganda 2006, Zambia 2007 <sup>(22)</sup>, Zambia 2013-14,

manuscript (report) writing of a variety of studies including cohort studies, clinical trials, national TB prevalence survey of Pakistan. She has provided technical assistance and assisted in building capacity for tuberculosis (TB) focused epidemiological and operational research in Asian and African countries. She supports several research projects from the department including statistical and epidemiological coaching of other scientist and MSc students. Since 2011 she is involved in the external monitoring and evaluation of the TB REACH initiative of the Stop TB Partnership. Before joining KIT, she has provided technical assistance and assisted in building capacity for epidemiological and operational research in Asian and African countries. She published over 30 articles in international peer-reviewed journals and was involved in writing of numerous (unpublished) reports. Since May 2015 she is associated editor for BMC Infectious Diseases, TB section.

### **3. Profile of the organization and track record**

#### **3.1 Profile of the organization**

The Royal Tropical Institute (KIT) is an independent and not-for-profit knowledge and expertise centre for international and intercultural cooperation active since 1910 and involved in more than 50 countries. KIT is officially registered as an Association with Full Legal Capacity. KIT has developed a Quality Assurance System, which allows us to monitor project management and processes. This system is both for the benefit of our organization as well as our clients as it facilitates continuous improvement of processes. KIT Management Team is closely involved in the monitoring process, through means of mission and project reports, financial reporting and visits to target countries and partner organizations. In addition, KIT actively seeks (peer) feedback from clients and partners (such as universities, governments, UN and NGOs) to ensure quality, innovation and appropriateness of our products and services.

#### **3.2 Track record**

##### **Predictive statistical modelling to inform TB incidence, prevalence and mortality estimates (2015 – ongoing) Client: WHO**

Development of predictive statistical ecological models for TB incidence, TB prevalence and TB mortality (among HIV-negative individuals) and assessing the usefulness of these models to determine TB burden and progress towards the 2015 targets at global, regional and country levels. Principal Component Analyses have been conducted to construct several variables.

##### **Nationwide TB prevalence survey in Pakistan (February 2012 to September 2012) Client: KNCV Tuberculosis Foundation (KNCV)**

KIT consultancy agreement to conduct the preliminary data analyses of the National TB Prevalence Survey in Pakistan. Before this consultancy KIT epidemiologist supported the protocol development, development of standard operating procedures, and pilot study of this survey while employed by KNCV.

##### **Geographic Information Systems for TB Project in Uganda, Benin and Ethiopia (2005 - 2011) Client: TB CAP, KNCV Tuberculosis Foundation (KNCV)**

In collaboration with KNCV Tuberculosis Foundation (lead) and the International Union Against Tuberculosis and Lung Disease to provide assistance for laboratory strengthening in the framework of TB CAP and TB CARE the KIT has set up a GIS component to monitor and evaluate the routine TB laboratory services and the External Quality Assessment Program.

##### **Stigma assessment and reduction impact (SARI) (2007-2009). Client: Netherlands Leprosy Relief (NLR)**

KIT advisors provided a detailed description of stigma reduction strategies and development of tests and methods for assessing effectiveness of strategies used in community-based rehabilitation projects for reducing leprosy-related stigma and, in this way, facilitation of persons with leprosy to reach and maintain wellbeing and functioning at all levels, reach social inclusion and quality of life

on the basis of equality with others.

**International Workshop on Health-related stigma and discrimination (2004-2005) Client: Various stakeholders**

KIT organized a workshop attended by participants representing 55 academic institutes, organisations, and health projects in Europe, Africa, Asia, North and South America. The workshop was characterized by an integrated, multidisciplinary and intercultural approach to healthcare issues relating to stigma and discrimination. In three working groups the participants studied and discussed the conceptual features of stigma, various strategies and interventions towards stigma reduction, and methods to measure diverse aspects of stigma and discrimination. Among the participants were persons with personal experience of stigma as a result of leprosy, HIV/AIDS and physical disability. Heijnders and Vander Meij (2006) paper outlining a geography of health stigma is a widely cited framework for health stigma intervention planning.<sup>10</sup>

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<sup>10</sup> Heijnders, M., and S. Van Der Meij. 2006. The fight against stigma: An overview of stigma reduction strategies and interventions. *Psychology, Health and Medicine* 11, no. 3: 353–63.



## 4. Budget

We estimate 34 person days of work to bring this sub-contract to completion, associated with a budget of USD 34,000 (daily fee USD 1,000). The breakdown per activity and timeline are presented in Table 1 Of note:

- 1) The allocation of days and budget assume that datasets will be provided in a ready to analyse format and that only minimal data management tasks will be necessary
- 2) We have not budgeted any travel costs for the Stigma Expert Meeting February 11<sup>th</sup>&12<sup>th</sup>, 2016. Based on the information provided in the call 'Correlates of Enacted TB Stigma' in Health Care settings we conclude that this meeting takes place in the Hague, the Netherlands.

#### 4.1 Table 1. Time frame and person days

|  |  | Person days | 10-okt | 17-okt | 24-okt | 31-okt | 7-nov | 14-nov | 21-nov | 28-nov | 5-dec | 12-dec | 19-dec | 26-dec | 2-jan-16 | 9-jan-16 | 16-jan-16 | 23-jan-16 | 30-jan-16 | 6-feb-16 | 12-feb-16 | 19-feb-16 | 26-feb-16 | 5-mar-16 | 12-mar-16 | 19-mar-16 | 26-mar-16 | 2-apr-16 | 9-apr-16 | 16-apr-16 | 23-apr-16 | 30-apr-16 | 7-may-16 | 14-may-16 | 21-may-16 | 28-may-16 | 4-jun-16 | 11-jun-16 | 18-jun-16 | 25-jun-16 | 2-jul-16 | 9-jul-16 | 16-jul-16 | 23-jul-16 | 30-jul-16 | 6-aug-16 | 13-aug-16 | 20-aug-16 | 27-aug-16 | 3-sep-16 | 10-sep-16 | 17-sep-16 | 24-sep-16 | 1-okt-16 | 8-okt-16 | 15-okt-16 | 22-okt-16 | 29-okt-16 | 5-nov-16 | 12-nov-16 | 19-nov-16 | 26-nov-16 | 3-dec-16 | 10-dec-16 | 17-dec-16 | 24-dec-16 | 31-dec-16 |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |    |
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## *Core Measurement Stigma*

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### **KIT proposal**

### **for support to the Challenge TB APA 1 Work Plan for Core Measurement Stigma**

*Correlates of Enacted TB Stigma in Health Care Settings*

**October 2015**

Sandra Alba, Mirjam Bakker, Masja Straetemans

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# 1. Analysis Plan

## 1.1 Data collection and data management

In the request for proposals 7 service provision assessments (SPA) surveys are listed in 6 different countries<sup>11</sup>. SPA surveys usually consist of several tools: Facility Audit Questionnaires, Observation Protocols, Client Exit Interviews and Health Worker/Provider Interviews. On average eight Health Care Workers (HCW) are interviewed per selected facility. Surveys are split into two groups based on the type of stigma questions present in the Health Worker Interview. In the most recent surveys indirect questions are used. Global positioning system (GPS) readings are done for each health facility (HF) in Kenya (sample) and Namibia (census).

We propose that the preparation of datasets (e.g. align variables from different surveys with regard to naming/coding; have a HF ID throughout all datasets) will be performed by skilled Data Management services facilitated by KNCV Tuberculosis Foundation. In this proposal we assume that we are provided with clean datasets of the Health Worker Interviews, Facility Audit Questionnaires<sup>12</sup> and GPS readings<sup>13</sup> of all selected SPA surveys including accompanying metadata (e.g. database specifications, codebooks or dictionaries). However, if this will not be possible due to availability of the Data Management services, we could do this task as well, but that will have consequences for the realistic time line and budget of this proposal.

## 1.2 Exploratory phase

Exploratory data analysis (EDA) will be mainly conducted on the HCW data to provide a narrative overview of data available from the eligible datasets, but will also study the Facility Audit data. The main aim is to understand the indirect and direct stigma/discrimination questions and to identify the underlying relationships between the measured variables at HCW level. We will summarize the data numerically and graphically by survey, identify missing values and determine its extend and choose course of action if required. In this step we will also explore possible variable transformation if appropriate. This phase will lead to a detailed data analysis plan which will be developed and discussed with KNCV Senior Epidemiologist, Ellen Mitchell.

## 1.3. Developing a stigma score

We propose to develop HCW stigmatizing scores profiling HCWs to the level of perceiving stigma (indirect stigma) and stigmatizing (direct stigma). These scores will be based on answers to multiple questions (Table 1). Averaging the HCW scores of each facility will provide a HF stigmatizing score. We will explore different ways of creating the stigmatizing scores among others by principal component analyses (PCA). We will aim to construct continuous scores with values between 0-100.

## 1.4 Analysis phase

The analysis will focus on 4 surveys with indirect PLHIV discrimination questions, which have been found to be more robust than direct measurement.

### 1.4.1 HCW level analysis (policy questions 2a,b, 3 and 4)

The aim of the HCW level analysis is to explore correlations between stigma and various characteristics of the HCWs (socio-demographic, cadre, attitudes, trainings received, supervision) and HFs. We propose to focus these analyses using our HCW stigmatizing scores as dependent variable, but can also include other individual response categories (Table 1 and figures 1). HCW willingness to report HCF discrimination (question 910, table 1) will also be used as separate dependent variable (Figure 2). Individual level (HCW) univariate and multivariate multi-level linear regression models will be fitted, including random effect for country and facility (if needed), and fixed effect for time (if needed), accounting for weighing implicit to survey structure, to study associations with stigma.

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<sup>11</sup> We identified a SPA survey in Rwanda (2007) which seems to have used the same indirect stigma related questions. This survey could potentially be added to the analysis.

<sup>12</sup> For efficiency purposes a selection of variables could be made from both sources. Selection to be made in conjunction with KNCV epidemiologist.

<sup>13</sup> KNCV epidemiologist responded to our question (email 5-10-2015) that data download is already approved and thus available in house with the exception of the GIS data for the SPA surveys. Additional application process for this needs to be started and this will influence the timeline with an unknown period.

Figure 1: Conceptual framework of perceived discrimination (i.e. enacted stigma)

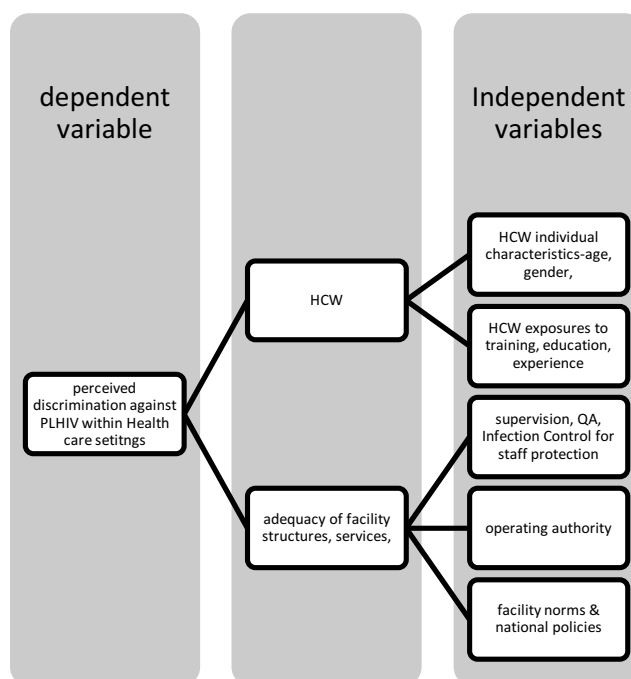
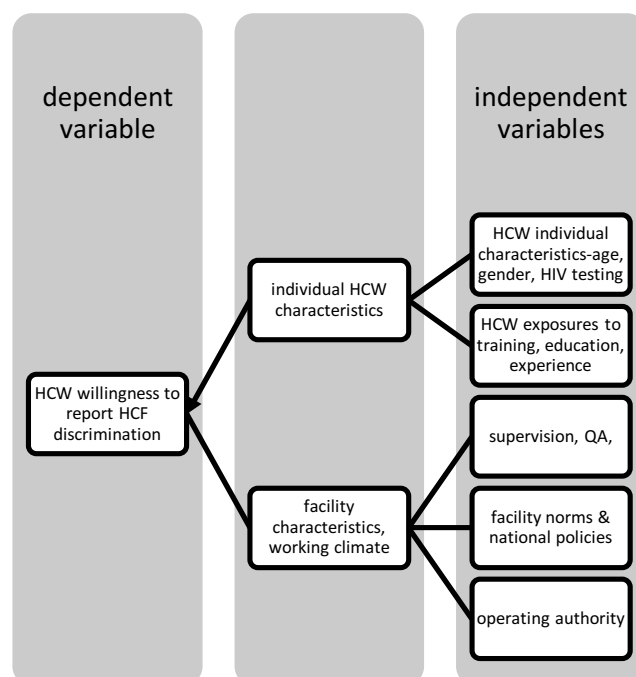


Figure 2: Conceptual framework of behavioural implications of perceived discrimination (i.e. enacted stigma)



#### 1.4.2 HF level analysis (policy question 1)

The aim of the HF level analysis is to explore correlations between the degree of stigmatisation perceived at a facility (based on the HF stigmatization score) and HF characteristics such as type and size of facility, services available and infection control practices. Only Kenya and Namibia have infection control variables relevant to TB. Health facility level univariate and multivariate models will be fitted as described above, only if the HCW level analysis will not provide sufficient answers to the questions. HCW level models will be repeated including data from Kenya and Namibia only including variables related to infection control.

We will map the HFs in the datasets of Kenya and Namibia using their GPS reading. We will show the perceived level of stigmatization of the HF (based on HF stigmatization scores). Separately we may also choose to map discrimination levels based on question 902 (Table 1). We will perform point pattern analysis for Kenya and Namibia to study the geographical distribution of stigmatization by testing for spatial autocorrelation. In case of spatial autocorrelation, we possibly use SatScan to identify stigmatization/discrimination hotspots.

#### 1.4.3 Intra facility variation (policy question 2c)

We will estimate the variation of the HCW stigmatizing scores within each facility by calculating the variance of the scores of the HCWs of each facility. We will explore which HF characteristics (if any) are associated with more (or less) variation. We will compare the within HF variation with the between HF variation.

#### 1.4.4 Considerations

The surveys with the direct stigma questions have been carried out 10 or more years ago. We will investigate how much levels of enacted stigma and discrimination have changed over time. The question 902/502 (Table 1) was used in all surveys and will be used to study whether there is a time trend. Time and location will be used to model stigma. If time explains variation more than location (country), the more recent surveys with indirect stigma questions may be more appropriate to focus on.

We have to be cautious not to over-interpret the data and introduce a researcher bias. Where possible stigma experts should be involved in interpreting response profiles preferably before the majority of the analyses are done.

**Table1. Overview of stigma related questions used in SPA surveys.**

| <b>Indirect questions – unspecified stigma</b> (Kenya 2010; Namibia 2009; Tanzania 2006 <sup>14</sup> Rwanda 2007) from Health Worker Interview: Section 9: Working with HIV/AIDS clients: |  |
|--|--|
| 902 <sup>14</sup>  | Do you think that a health care worker who has HIV but is not sick, should be allowed to continue work? (Y/N/DK)   |
| 903  | In the past 12 months, have you seen or observed the following happen in this healthcare facility because a client was known or suspected of having HIV/AIDS? (read each scenario below) (Y, N, NA, DK)<br><br>01 Testing a client for HIV infection without their consent; 02 Requiring some clients to be tested for HIV before scheduling surgery; 03 Using latex gloves for performing non-invasive exams on clients suspected of HIV; 04 Extra precautions been taken in the sterilization of instruments used on HIV-positive patients; 05 Health providers gossiping about a client's HIV status; 06 Because a patient is HIV-positive a senior provider pushing the client to a junior provider; 07 An HIV-positive patient receiving less care/attention than other patients. |
| 904  | Have you ever heard of the word stigma? (Y/N)  |
| <i>HCW perceptions of the presence of (HIV) discrimination (enacted stigma) within their health facility</i>   |  |
| 905  | Does stigma occur in health facilities? (Y/N/uncertain-DK)   |
| 906  | Please give me some examples of stigma in the health facility (open ended with 6 pre-specified possibilities similar to the scenarios of 903 and other)  |
| <i>HCW perceptions of the presence of (HIV) discrimination (enacted stigma) in the community</i>   |  |
| 907  | Does stigma occur outside health facility? (Y/N/uncertain-DK)  |
| 908  | Where have you observed or heard stigma occur? (open ended with 5 pre-specified possibilities and other)   |
| 909  | Please give me some examples of stigma that occur outside health facility (open ended with 5 pre-specified possibilities and other)  |
| 910  | If you ever saw any of the above types of stigma happening to a person because s/he is a PLWHA, would you be willing to inform the authorities or relevant groups if they existed? (Y/N/DK)  |

<sup>14</sup> Numbering used in Kenya 2010 and Namibia 2009 surveys; numbering in Tanzania 2006 surveys slightly deviate from this.

## 2. Experts

We propose a strong team comprising of three PhD level scientist including a medical statistician, TB epidemiologist and an epidemiologist / geographic information expert.

**Sandra Alba, MSc, PhD**, is a medical statistician/epidemiologist at KIT. She obtained an MSc in Medical Statistics at the London School of Hygiene and Tropical Medicine in 2006, and soon after joined the Swiss Tropical and Public Health Institute for a PhD project. She contributed to the epidemiological design, designing data collection tools, coordinating fieldwork as well as data analyses and reporting of an evaluation study of a program aimed at improving and understanding access to malaria treatment in rural Tanzania. Data used for the evaluation consisted of cross-sectional community surveys as well as secondary analysis of demographic surveillance systems (DSS) and health management and information systems (HMIS) data. After completing her PhD in 2010, she spent two years working as a clinical trial statistician in a Contract Research Organisation based in Switzerland. Through this experience she developed expertise in analysing and reporting clinical trial data. During this time she taught various courses on clinical trial statistics for professionals of the pharmaceutical industry, and participated in the teaching of a module on Data Analysis in Epidemiology for the MSc course in Epidemiology of the Swiss TPH. At the end of 2012 she joined the KIT as a medical statistician/ epidemiologist, where she continues to be involved in epidemiological studies and evaluations of health interventions for the control of infectious diseases both in Europe and Africa. Her responsibilities further include teaching statistical and epidemiological methods to post-graduate students as well as supervising MSc students

**Mirjam Bakker, Ph.D.**, senior epidemiologist, is coordinator of a small group of epidemiologists/geographic information system (GIS) experts at KIT. Specialized in epidemiology of infectious diseases, she has extensive experience in the use of GIS in disease control, in operational/field research of tuberculosis (TB) and HIV care and prevention and in monitoring and evaluating TB case finding activities. She has been involved in several large epidemiological field studies in, among others, Indonesia, Rwanda and Malawi. She contributed to the epidemiological design, data collection, data-entry, data analyses, and reporting and developed specific expertise in the use of GIS linking spatial, demographic and health data to study transmission patterns and disease clustering. She was responsible for developing the course “Using GIS in disease control programmes”, which she teaches on a yearly basis, furthermore she gave several GIS workshops. From the start in 2010 she was involved in the external monitoring and evaluation of the TB REACH initiative of the Stop TB Partnership. She was engaged in the development of the M&E framework and responsible for the overall compilation of results of over 100 projects. She supervises M.Sc. and Ph.D. students and is proficient in using STATA, ArcGIS and QGIS.

**Masja Straetemans, PhD** is a senior epidemiologist KIT. She obtained a Master of Science (MSc) in Environmental Health Sciences and a PhD in Epidemiology. She has over fifteen years of experience in epidemiological research at the university of Nijmegen (the Netherlands), the Centre for Disease Control and Prevention (USA), the Robert Koch Institute (Germany), the European Centre for Disease Prevention and Control (Sweden) and KNCV Tuberculosis Foundation (the Netherlands). She has been involved in study design, study implementation, data analyses and manuscript (report) writing of a variety of studies including cohort studies, clinical trials, national TB prevalence survey of Pakistan. She has provided technical assistance and assisted in building capacity for tuberculosis (TB) focused epidemiological and operational research in Asian and African countries. She supports several research projects from the department including statistical and epidemiological coaching of other scientist and MSc students. Since 2011 she is involved in the external monitoring and evaluation of the TB REACH initiative of the Stop TB Partnership Before joining KIT, she has provided technical assistance and assisted in building capacity for epidemiological and operational research in Asian and African countries. She published over 30 articles in international peer-reviewed journals and was involved in writing of numerous (unpublished) reports. Since May 2015 she is associated editor for BMC Infectious Diseases, TB section.

### **3. Profile of the organization and track record**

#### **3.1 Profile of the organization**

The Royal Tropical Institute (KIT) is an independent and not-for-profit knowledge and expertise centre for international and intercultural cooperation active since 1910 and involved in more than 50 countries. KIT is officially registered as an Association with Full Legal Capacity. KIT has developed a Quality Assurance System, which allows us to monitor project management and processes. This system is both for the benefit of our organization as well as our clients as it facilitates continuous improvement of processes. KIT Management Team is closely involved in the monitoring process, through means of mission and project reports, financial reporting and visits to target countries and partner organizations. In addition, KIT actively seeks (peer) feedback from clients and partners (such as universities, governments, UN and NGOs) to ensure quality, innovation and appropriateness of our products and services.

#### **3.2 Track record**

##### **Predictive statistical modelling to inform TB incidence, prevalence and mortality estimates (2015 – ongoing) Client: WHO**

Development of predictive statistical ecological models for TB incidence, TB prevalence and TB mortality (among HIV-negative individuals) and assessing the usefulness of these models to determine TB burden and progress towards the 2015 targets at global, regional and country levels. Principal Component Analyses have been conducted to construct several variables.

##### **Nationwide TB prevalence survey in Pakistan (February 2012 to September 2012) Client: KNCV Tuberculosis Foundation (KNCV)**

KIT consultancy agreement to conduct the preliminary data analyses of the National TB Prevalence Survey in Pakistan. Before this consultancy KIT epidemiologist supported the protocol development, development of standard operating procedures, and pilot study of this survey while employed by KNCV.

##### **Geographic Information Systems for TB Project in Uganda, Benin and Ethiopia (2005 - 2011) Client: TB CAP, KNCV Tuberculosis Foundation (KNCV)**

In collaboration with KNCV Tuberculosis Foundation (lead) and the International Union Against Tuberculosis and Lung Disease to provide assistance for laboratory strengthening in the framework of TB CAP and TB CARE the KIT has set up a GIS component to monitor, evaluate the routine TB laboratory services and the External Quality Assessment Program.

##### **Stigma assessment and reduction impact (SARI) (2007-2009). Client: Netherlands Leprosy Relief (NLR)**

KIT advisors provided a detailed description of stigma reduction strategies and development of tests and methods for assessing effectiveness of strategies used in community-based rehabilitation projects for reducing leprosy-related stigma and, in this way, facilitation of persons with leprosy to reach and maintain wellbeing and functioning at all levels, reach social inclusion and quality of life on the basis of equality with others.

##### **International Workshop on Health-related stigma and discrimination (2004-2005) Client: Various stakeholders**

KIT organized a workshop attended by participants representing 55 academic institutes, organisations and health projects in Europe, Africa, Asia, North and South America. The workshop was characterized by an integrated, multidisciplinary and intercultural approach to healthcare issues relating to stigma and discrimination. In three working groups the participants studied and discussed the conceptual features of stigma, various strategies and interventions towards stigma reduction, and methods to measure diverse aspects of stigma and discrimination. Among the participants were persons with personal experience of stigma as a result of leprosy, HIV/AIDS and physical disability.



#### 4. Budget and time line

We estimate 23 person days of work to bring this sub-contract to completion, associated with a budget of USD 23,000 (daily fee USD 1,000). The breakdown per activity and timeline are presented in Table 2. Of note:

- 3) The allocation of days and budget assume that datasets will be provided in a ready to analyse format and that only minimal data management tasks will be necessary
- 4) We have not budgeted any travel costs for the Stigma Expert Meeting February 11<sup>th</sup>&12<sup>th</sup>, 2016. Based on the information provided in the call 'Correlates of Enacted TB Stigma' in Health Care settings we conclude that this meeting takes place in the Hague, the Netherlands.

**Table 2. Time frame and person days**

[illegible]

### **Protocol of a Systematic Literature Review of Interventions to Reduce TB Stigma**

Authors: Nina Sommerland, Ellen M.H. Mitchell, Millicent Ngicho, Caroline Masquillier, Annelies Van Rie, Edwin Wouters,

#### **Background and theoretical framework of Stigma**

Even though a curable disease, since 2014 Tuberculosis (TB) has become the world's leading infectious disease killer (1). The epidemic has existed for millennia, but public health efforts have been hampered by pervasive stigma (2). Stigma, as originally defined by Goffman is a process of differentiation and othering which can cause discrimination and modified behavior for those targeted (3). Stigma occurs when a certain characteristic, in this case TB, is negatively regarded and the person labeled is devalued. Manifestations of stigma can include outward, negative attitudes, perceptions and behaviors, but also negative self-perception and internalization of the tainted identity. TB stigma may cause a delay in treatment and hinder elimination effort. For the same reasons, stigma can affect adherence to a treatment program (4, 5). Due to feared and actual mistreatment of people living with TB, some people do not seek diagnosis or treatment. (6) (7) (8).

Since stigmas of different types are actively created in societies and can look different across time and space, they can also change and be reduced or disappear (9, 10). Link and Phelan (11) posit that stigma is constructed via a cascade of interrelated social processes. To reduce stigma, disparaging social norms, structures and behaviors need to be defined and dismantled. To create stigma, people must first draw attention to distinctions between people (e.g. infected vs. uninfected, diseased vs. non-diseased).

Then in the second stage, the distinctions are further labelled in ways that may or may not be representative of the group (e.g. 'contagious disease of poverty'). Then additional (often spurious) characteristics are rhetorically attributed to the labelled group (e.g. 'suspect', 'dirty', 'poor', 'unhygienic') with the intent of marking social distance between groups. Systematically linking undesirable characteristics to the group gradually forms a stereotype. The prejudices fostered by these stereotypes develop quickly and often without reflection. People quickly associate a certain characteristic with a certain group, even if this association defies logic or has no empirical basis (11, 12). Negative stereotypes connected to TB patients have bundled TB with immorality, frailty, hedonism, effeminacy, self-destruction (13, 14). Some of these assigned labels have a profound impact on people's life chances. The negative characteristics and values ascribed to a stigmatized group may occur consistently across countries or may vary depending on the social, economic and cultural forces. Lack of knowledge about the trait can also foster stigma.

The process of stigmatization is complete when the deprecating beliefs about the group eventually become taken for granted. Notions of infantilism and untrustworthiness of TB patients are enshrined in the concept of direct observation of treatment. The conscious creation of an "us versus them" dynamic helps to reinforce hierarchies of power and value.. This form of "othering" can

lead to various consequences for the targeted group. For people with TB, social relations are often negatively affected as both community members and care givers can be reluctant to socialize- or be associated with TB patients (13, 15)

Group with the most societal power can leverage stereotypes to justify isolating, discounting, patronizing or discriminating against those with the stigmatized trait. Stigmas can be used to withhold quality health care, education, housing and employment to certain groups. Stigmas limit group access to the labor market and marriage and family formation (16).

### **Typology of stigmas**

Stigma is often explained as three different types of stigmas that can be applied to people living with TB: anticipated, internalized and enacted stigma (17).

*Anticipated stigma* - refers to the imagining of the prejudices, discrimination and negative attitudes that a person would experience if they were to have the tainted identity. An intervention to reduce anticipated TB stigma could be a social media campaign depicting manifestations of compassion and solidarity with TB patients as normative.

*Internalized stigma* is the degree to which someone believes themselves to possess the negative traits that are assumed to be associated with the stigmatized characteristic. An intervention to reduce internalized TB stigma could be a self-help group where patients counter negative feelings and thoughts with social approval and role modelling empowerment.

*Enacted stigma* refers to lived experiences of discrimination and mistreatment (18). An intervention to reduce enacted TB stigma could be a video reflection experience where doctors watch video of themselves providing care to TB patients and conduct self-assessment of their verbal and non-verbal cues using a standard checklist. Information campaigns aimed toward the general community to contest negative stereotypes of people with TB can also lead to improved behavior and treatment towards them.

Interventions aimed to reduce stigma can target one or several types at the time, directly or indirectly. For example, incentives to improve societal attitudes toward people with TB can lead to a reduction in both enacted and anticipated stigma. Observed changes in behavior toward people with TB could thus lead to a decreased anticipation of stigma.

### **Rationale**

From this theoretical point of view, stigma can also change and be reduced. Efforts to do so are imperative due to the social and practical consequences suffered by stigmatized people. In designing interventions aimed to reduce stigma, several dimensions can be targeted, from focusing on a small particular group to trying to change general attitudes. A narrow focus on stigma reduction can be beneficial since results might be easier to measure, but looking to the conceptual framework of the interchanging components, one must observe that treating a small part might not address the underlying societal problem if reductions are to be sustained over time. This is why much research on stigma

promotes a multi-level approach and to use interventions on all socio-ecological levels (11).

Studies of interventions attempting to reduce TB stigma have been conducted but there is no current consensus on what interventions may be most effective in reducing stigma across a variety of settings. To identify or hypothesize the most effective elements and approaches, it is necessary to perform a systematic literature review of previous interventions which aim was to reduce TB stigma. In this way interventions with potential effectiveness could be considered for future testing.

### **What is a tuberculosis (TB) stigma reduction intervention?**

The operational definition of a TB stigma reduction intervention is a set of coordinated actions implemented at the individual, institutional, or societal level to identify and positively influence social norms and behaviors, reduce discrediting attitudes and derogatory behaviors (enacted stigma) that negatively impact the experience, health-seeking behavior and treatment outcomes of people living with TB.

Effective TB stigma reduction interventions are defined as programs that lead to primary outcomes such as:

- Improved attitudes toward people living with TB
- Improved social norms –e.g. re-framing of TB as a transient, curable condition affecting good people
- Improved TB patient self-concept and self-efficacy,

They can also be part of larger interventions that contribute to downstream outcomes such as:

- Improved experiences in TB treatment
- Improved treatment adherence- and outcomes

### **Objective**

To systematically review the literature assessing the effectiveness of interventions that aim to reduce TB stigma, including studies describing and explaining how they work.

### **PICO questions**

1. What interventions are effective in improving the attitudes and behaviors among the general public toward people living with TB?
2. What interventions are effective in improving the self-concept and self-efficacy of TB patients?
3. What interventions are effective in improving the behavior of care-givers, including healthcare workers, toward TB patients?

## Methods

### Selection criteria

#### Types of studies

Since the body of studies reducing TB stigma is expected to be limited, we will include a broad range of possible study designs: both qualitative and quantitative. They will be thematically reconciled in the analysis based on the three different types of stigma. All types of studies will be assessed for bias by fitting scales but the outcome measurements will be compared based on study design. Since TB stigma is not geographically restricted, studies from any country will be considered. Following is a list of included study types:

1. *Experimental design studies*. Controlled trials randomized on either individual or group level.
2. *Quasi experimental studies* with longitudinal or cross-sectional designs. Appropriate matching variables for intervention and control groups could be baseline stigma (or the relevant operationalization of stigma) measurement, living- or working environment and socio-demographic characteristics depending on if the intervention targets TB patients, HCP or the general population.
3. *Qualitative studies*. Both fully qualitative studies and complementary to quantitative research can be relevant to our review, if they describe and analyze an intervention with the aim to reduce TB stigma. Qualitative pilot studies are also of interest. The studies should have a theoretical framework defining stigma. Data can be collected through focus groups, interviews and observation.
4. *Mixed methods studies*. Often quantitative intervention studies have a qualitative component used to enhance or test the results of a quantitative trial. We will use complementary studies that fit the overall purpose with the research project to decrease TB stigma. Each partial study is subject to the same inclusion criteria as wholly quantitative or qualitative studies.
5. *Review studies*. Qualitative, mixed or quantitative synthesis of evidence of interventions aimed to reduce TB stigma will be included. The within synthesis studies' populations, study designs and interventions have to match the same criteria as the individual studies in our review.

#### Types of participants

In order to examine stigma prevention on all socio-ecological levels, studies will focus on three types of participants –the general public, persons with TB, and care givers, including health care workers. These groups are most often affected by TB stigma or targeted by interventions, be it as a stigmatized group or possible stigmatizers. The different types of participants can be targeted by interventions aimed to reduce one or several of the three types of stigma (see Table 1). When a population type is referred to in the review, it is the one whose

behavior is addressed by the intervention. This is not necessarily the same as the group who is meant to benefit from the intervention.

1. *The general public.* In areas where TB is prevalent, stigma often exists in the general community, even if a person does not have TB. Insufficient knowledge and fear of getting infected can have the effect of enacted stigma towards people with TB (19). Examples are denying people with TB the same right to work, marriage, and stereotyping assumptions that people with TB are dirty, have led a promiscuous lifestyle or are possessed by demons (4, 20). The general society can shun people with TB and contribute to anticipated and internalized stigma. The consciousness of the stigmatizing attitudes that affects people with TB also leads to anticipated stigma among the general community which can lead to an unwillingness to screen for TB and get diagnosed (6). This has made the general public a focus for many intervention campaigns (15).
2. *TB patients.* People who have TB often face stigma on several levels. Faced by the stereotyping and negative attitudes in society as well as discrimination, they can internalize the stigma into a negative self-perception (21). Internalized stigma can also manifest itself in a sense of shame and self-blame of having acquired TB (4).
3. *Care givers and health care professionals.* Since people with TB are dependent on functioning health care and TB stigma is proven to affect its prevalence and quality, care givers and health care professionals are of interest in stigma reduction (5, 22). Care givers and health care professionals can generate enacted stigma by showing negative attitudes toward TB patients and treat them lesser than other patients due to fear of contagion. They can also avoid TB patients due to anticipation of stigma from other health-care workers (5)

**Table 1. Matrix of 6 Possible Combinations of TB Stigma Reduction Efforts by Population Recipient of the Intervention**

|                                 | General public | TB patients | Health care workers and care givers |
|---------------------------------|----------------|-------------|-------------------------------------|
| Anticipated stigma              | 1              | 2           | 3                                   |
| Internalized stigma             |                | 4           |                                     |
| Enacted stigma (discrimination) | 5              | 6           | 7                                   |

### Types of interventions

Interventions with the aim to reduce TB stigma can look different depending on the target and context. Interventions may be in the form of special groups or clubs for TB-patients designed aimed towards increasing knowledge about TB in a general population. Interventions can also be initiatives to educate health care

professionals working with TB patients not to reproduce stigmatizing views on a patient. Interesting for the review are also interventions with a different primary focus than TB stigma, for example aimed to reduce stigma related to HIV/AIDS but where TB stigma is mentioned as a secondary outcome. Illustrative examples of types of interventions we will include are:

- information campaigns
- skill building through pre-service and in-service training, mentoring, supervision
- counselling
- contact/interaction

#### **Types of outcome measurements**

Since different intervention levels and study designs will be considered for this review, both proximate and longer term outcome measures are also likely to vary. We will include studies that use a proximate measure of stigma through clearly operationalized items. The intermediate purpose outcomes will be divided into the three types of stigma used to conceptualize the review, anticipated, internalized and enacted stigma.

Intermediate outcomes for interventions addressing anticipated stigma:

- Improved health care seeking by people who have- or presumed to have TB
- Quality of social relations between TB patients, families and the general community
- Social inclusion of people with TB
- Reduced time to health seeking for TB symptoms

Intermediate outcomes of successful interventions addressing internalized stigma:

- Improved Self-concept
- Improved perceived self-efficacy in TB treatment adherence
- Improved quality of social relations
- Improved quality of Life
- Improved mental health
- *Possibly: Increased disclosure of illness (A research question is whether disclosure = no stigma)*

Intermediate outcomes of successful interventions addressing enacted stigma:

- Fewer self-reports of discrimination, mistreatment in community, health care, and occupational settings by TB patients
- Fewer self-reports of denial and/or substandard care in health care settings
- Increased health care worker retention in TB field (HCW working in TB can be stigmatized too)

Distal outcomes of all the stigma interventions can include increased case detection, increased adherence, improved treatment outcomes, including survivorship.

#### **Search methods for identification of studies**

A comprehensive search strategy will be developed with the help of a medical librarian. Studies will be searched between 1990 and 2015, and the rather broad time period is chosen since we do not expect a large number of studies. The pre-chemotherapy era studies will be excluded because research has shown that availability of effective treatment has a profound effect in dismantling stigma, and those studies (if any exist) may no longer be applicable to modern stigma. Languages will include English, Spanish, Portuguese, German, Dutch, and French.

The Cochrane Search Strategy will be applied. Eight databases used for the search including

1. Pubmed
2. Cochrane Library
3. Ovid
4. EMBASE
5. PsycInfo
6. Sociofile
7. Sociological Abstracts
8. Google Scholar

The reference lists of relevant articles will be hand searched to find additional articles. In addition, since qualitative studies are of interest, other sources than the traditional databases will be searched. Greenhalgh and Peacock (23) showed that many qualitative studies are not found in conventional searches, so the so called "snowball strategy" and citation tracking will also be applied.

#### **Identification of unpublished studies**

Unpublished articles, reports, or conference abstracts may be considered for inclusion if they meet study criteria.

1. the World Health Organization website,
2. STOP TB partnership website,
3. STOP TB USA weekly digest,
4. The Centers for Disease Control and Prevention TB resource database,
5. KNCV Archives,
6. abstracts of the Union Conference on TB and Lung Disease from 2010-2015,

#### **Search Terms**

The search strategy will include the following keywords, using MeSH subject headings, exploded subject headings, publication type, subject hearing word, text word, title, and abstract:

1. TI = (tubercul\* OR lung tuberculosis OR pulmonary consumption OR consumption, pulmonary OR TB) AND



2. SU= ["stigma\*" OR "discrimination" OR "barriers" OR "attitud\*" OR "enable\*" OR "discredit\*" OR "self-efficacy" OR "self-concept" OR "discrimina\*" OR "inequ\*" OR "prejudic\*" OR "stereotyp\*" OR "social perception" OR "social isolation" OR "social inclusion" OR "disclosure" OR "patient-centered" OR "shame OR quality"] AND
3. SU= ["intervention" OR "program" OR "effect\*" OR "impact" OR "project" OR "trial" OR "experiment" OR outreach OR mobiliz\* OR grass-root\* OR community SAME perspect\* OR communit\* SAME involvement or community SAME particip\* or empower\* or grass-root\$ or civil society OR engage\* OR reduc\* OR improve\* OR address\*].

We will exclude studies with the following words in the title

TI = (vaccine OR BCG OR mice OR biopsy OR interferon-gamma OR pathophysiology\* OR genotyp\* OR bacille Calmette OR drug resistance survey\* OR re-vaccination OR candidate OR bovi\* OR mice OR deer OR cattle OR non-tubercul\* OR strain OR case report OR dose-response OR adverse OR possum OR macaque\* or guinea pig\* OR phenotyp\*OR animal model)

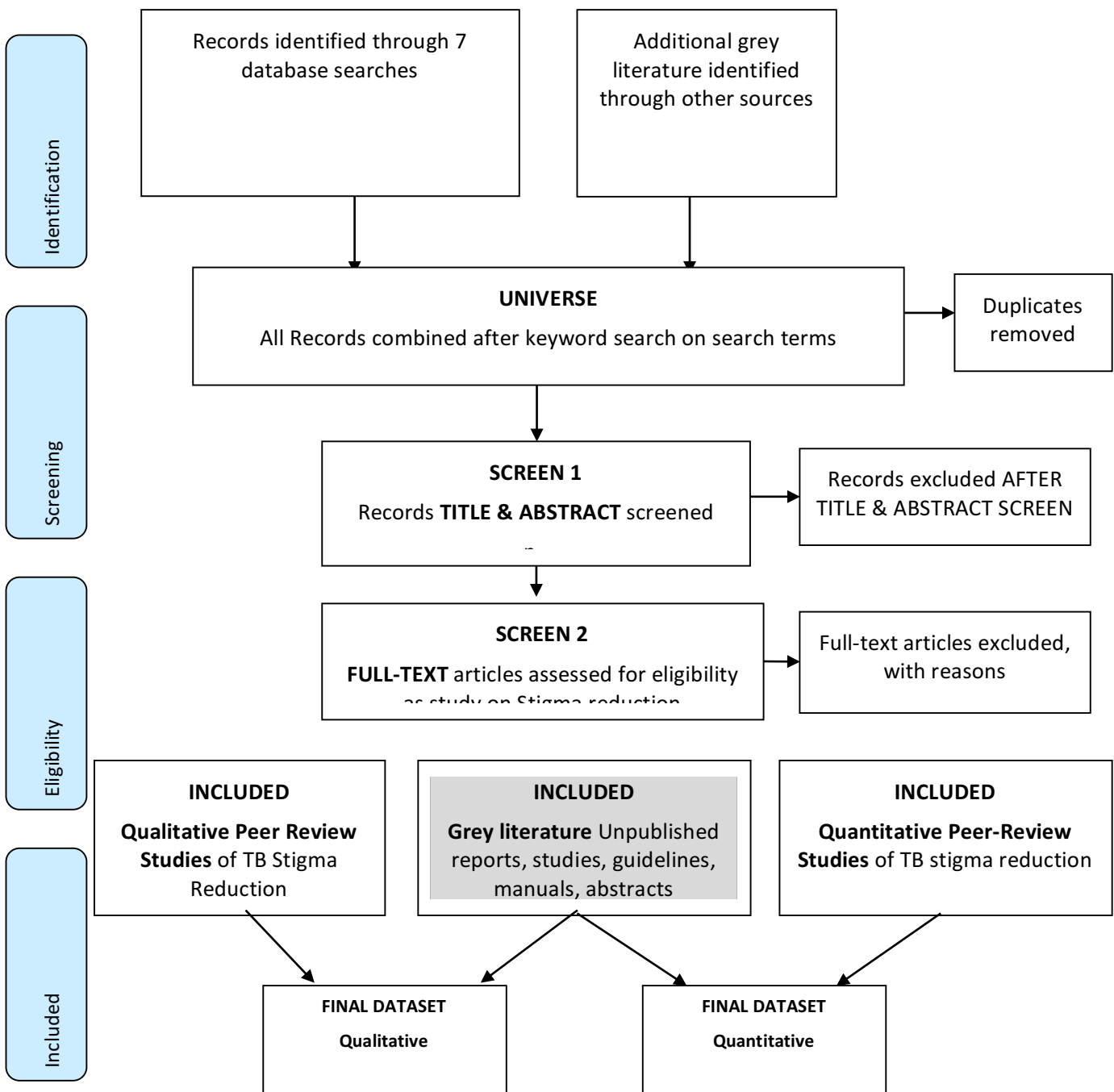
The reference lists of the identified studies will also be searched for relevant studies. Citations and article abstracts will be extracted from their respective databases into spreadsheets. Data from all databases will be combined and de-duplicated with Link Plus software.

#### **Data collection and analysis**

#### **Selection of studies**

The inclusion of studies in the review is illustrated in Figure 1.

**Figure 1: Literature Review**



## **Screen 1**

In the first screening step, potentially eligible studies will be selected for inclusion using broad criteria: (i) that the publication be original research; and (ii) titles, abstracts, or key words suggest that TB stigma reduction was attempted (review phase 1). Reasons for exclusion at this stage will not be recorded.

References will be reviewed for eligibility by two reviewers. Discrepancies will be resolved by consensus between two reviewers.

## **Screen 2**

In the second eligibility screen, the full text of all potentially eligible studies will be obtained. Each potentially eligible study will be reviewed by two reviewers using standardized eligibility criteria.

If there is a lack of consensus among the two reviewers for which studies are eligible, a third reviewer will be the tie-breaker. Reasons for exclusion of potentially eligible studies will be listed.

## **Data extraction and management**

The full papers of the remaining articles will be read by two researchers who will extract the agreed information to a data set.

## **Contact authors**

Authors will be contacted in the following situations:

1. If the validity or nature of the stigma measures used are unclear
2. If the evaluation method, other statistical methods, and design are unclear
3. If the change mechanism of the intervention is unclear

The following data will be extracted from the eligible articles into a data set (see appendix XX for detailed codebook):

- Publication info (author, year, country)
- Study design (i.e. RCT, repeated cross-sectional surveys, quasi-experimental with vs without control group, qualitative, review studies)
- Study populations (e.g. HCW)
- Attitude change techniques (e.g. mass media, infotainment, IEC materials)
- Behavioral change technique (e.g. feedback and monitoring, social support, shaping knowledge, identity, natural consequences, self-belief)
- Stigma type (anticipated, internalized, enacted)
- Scale for measuring stigma and validity
- Result (increase or decrease in stigma after intervention)
- Outcome used to assess effectiveness of intervention

## **Summary measures**

The following summary measures will be used to assess efficacy of the interventions. Studies with dichotomous outcomes:

Risk ratio (RR), (confidence interval 95 %), p-value

Odds Ratio (OR), (confidence interval 95 %), p-value

Studies with continuous outcomes:

Differences in means, (confidence interval 95 %), p-value

Difference in medians (with IQR) (confidence interval 95 %), p-value

The qualitative studies will be used primarily to provide understanding on the underlying mechanisms for decreasing TB stigma, such as behavior change technique.

## **Assessment of risk of bias**

The chosen studies will be assessed for outcome bias by two independent review authors according to standardized forms appropriate for the eligible types of designs. The quality assessment tools as described below covers risk of bias on both on a study level and outcome level. The results of the quality assessments will be published for each study in the review using the scales available for each tool.

### ***Tools for assessing risks of bias***

For experimental studies, we will use the Cochrane GRADE approach which ranges from high, moderate, low to very low, often illustrated with 1-4 stars (24). The GRADE approach defines the quality of a body of evidence as “the extent to which one can be confident that an estimate of effect or association is close to the quantity of specific interest”. The factors (taken from the *Cochrane Handbook for Systematic Reviews*) that can lower the quality grade are:

- Limitation of detailed design and execution (risk of bias criteria)  
Each randomized controlled intervention study is at risk for biased results due to various risk factors. Cochrane lists these biases as selection bias: the systematic differences between baseline characteristics of the groups that are compared. Performance bias: the systematic differences between groups in exposure to factors other than the interventions of interest. Detection bias: the systematic differences between groups in how outcomes are determined. Attrition bias: the systematic differences between groups in withdrawals from a study and reporting bias: the systematic differences between reported and unreported findings.
- Inconsistency (or heterogeneity)  
Statistical heterogeneity, which is referred to here, is a consequence of clinical or methodological diversity, or both, among the studies. Statistical heterogeneity manifests itself in the observed intervention effects being more different from each other than one would expect due to random error (chance) alone.
- Indirectness (PICO and applicability)  
An example of indirectness is that a review may find randomized trials that meet eligibility criteria but which address a restricted version of the main review question in terms of population, intervention, comparator or outcomes.

- Imprecisions (number of events and confidence interval)  
When studies include few participants and few events and thus have wide confidence intervals, authors can lower their rating of the quality of the evidence
- Publication bias  
When investigators fail to report studies (typically those that show no effect: publication bias) or outcomes (typically those that may be harmful or for which no effect was observed: selective outcome reporting bias) on the basis of results. If publication bias is suspected, the author of the report will be contacted for provision of missing data.

The Newcastle-Ottawa scale will be used for non-randomized and case-control trials (25). As with the Cochrane scale, the measurement consists of four levels of quality, but the influencing factors are

- Selection and representativeness of cases
- comparability of groups
- exposure to treatment.

For qualitative individual studies, the Cochrane group recommends Spencer's and colleagues' guidelines as a way of assessing quality (24, 26). Based on a review of evaluation strategies on qualitative studies, four central guiding principles was the framework of 18 assessment questions:

- contributory in advancing wider knowledge or understanding about policy, practice, theory or a particular substantive field;
- defensible in design by providing a research strategy that can address the evaluative questions posed;
- rigorous in conduct through the systematic and transparent collection analysis and interpretation of qualitative data;
- credible in claim through offering well-founded and plausible arguments about the significance of the evidence generated (26) pp.7.

Since we also expect review studies (qualitative) of stigma interventions we will use The Confidence in the Evidence from Reviews of Qualitative research (CERQual) (27) for quality assessment. Four components contribute to an assessment of confidence in the evidence for an individual review finding:

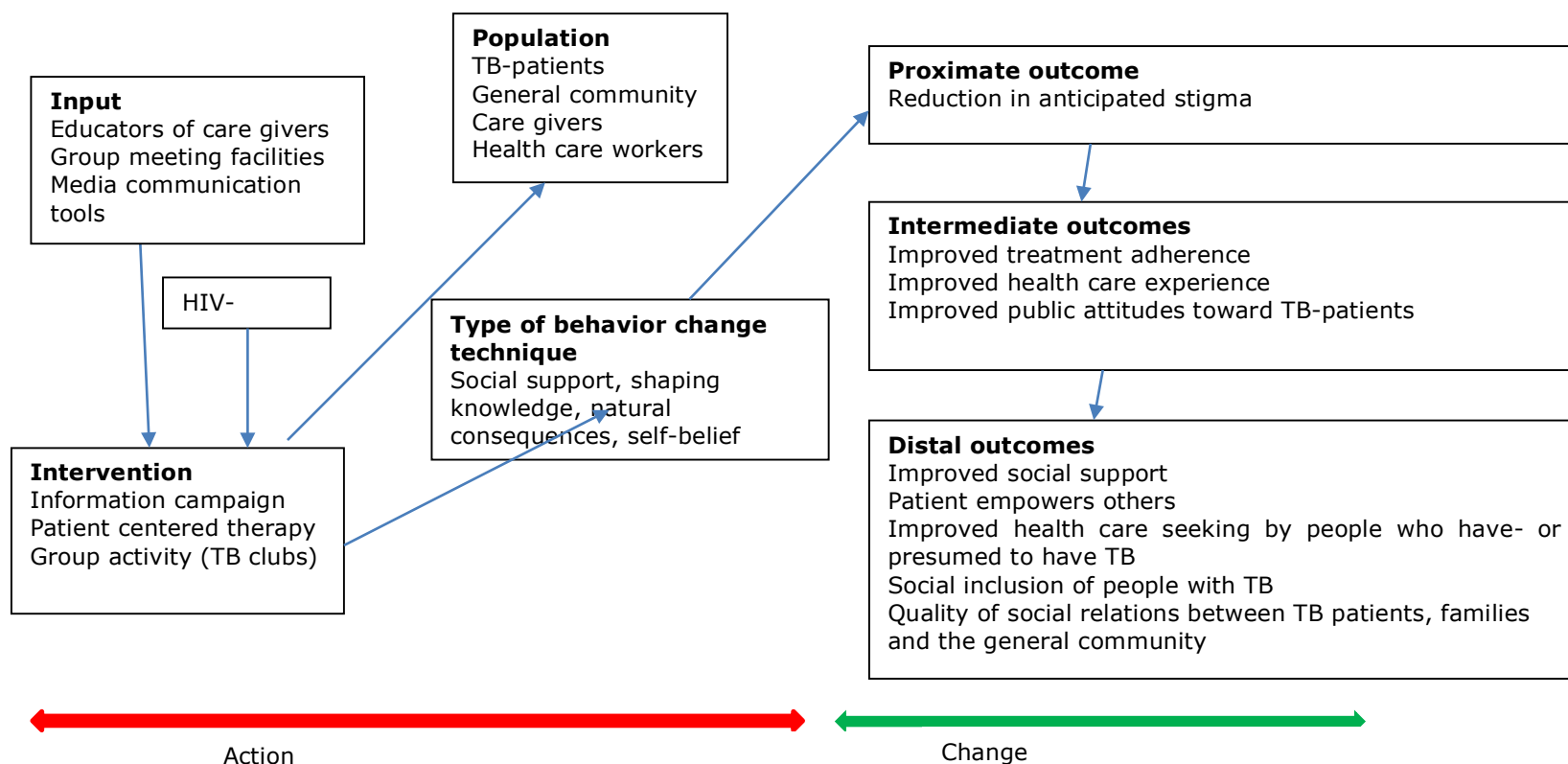
- methodological limitations,
- relevance
- coherence
- adequacy of data

### **Data synthesis**

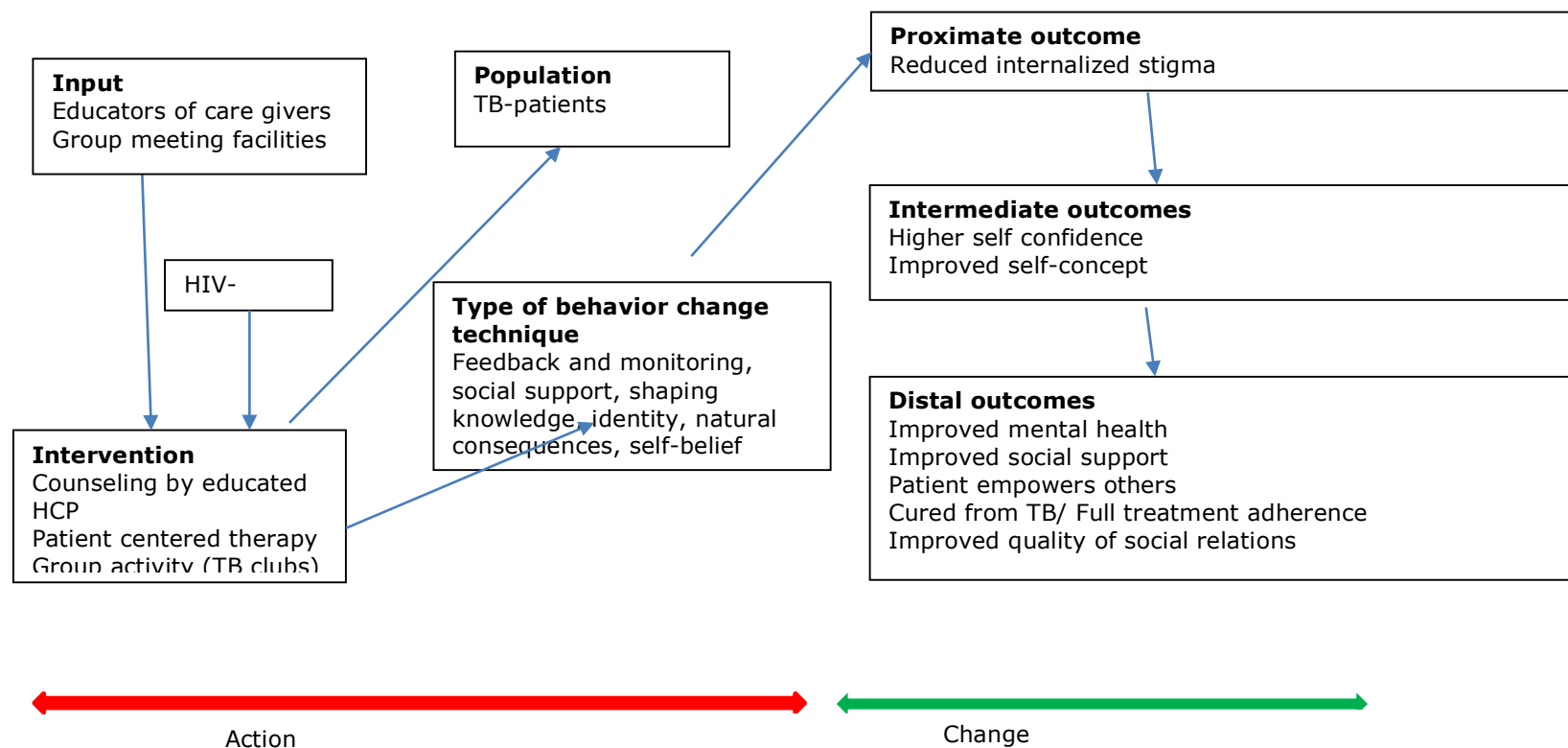
The results will in this protocol be presented in a logic model for each of the stigma types, inspired by the guidelines of Kneale and colleagues (28). The models will help describing how interventions might work in the protocol and will contribute to a synthesis of the results in the review report. The purpose is to identify the key stages of an intervention process to help guide the later stages of the review.

The data analysis will be descriptive since it is highly unlikely that the search will yield a sufficient amount of similar studies for a meta-analysis.

**Figure 2: Illustrative Logic model for an Intervention to Reduce Anticipated stigma**

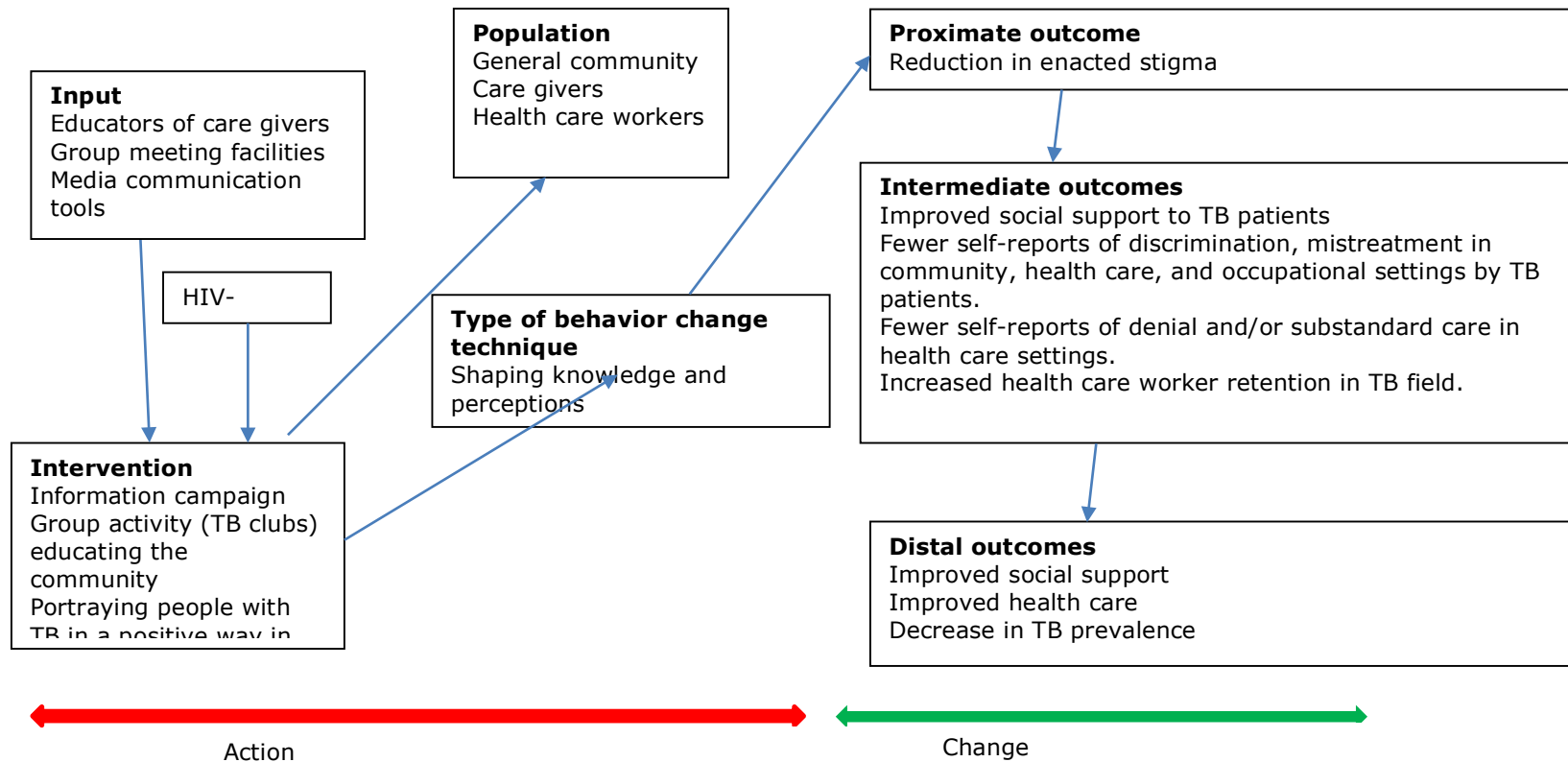


**Figure 3: Illustrative Logic model for an Intervention to Reduce Internalized stigma**





**Figure 4: Illustrative Logic model for an Intervention to Reduce Enacted stigma**



# Inclusion criteria

## FIRST ELIGIBILITY SCREEN

| Variable                | Explanation   | Answer categories  |
|-------------------------|---|--|
| <b>study_id</b>         | Individual study ID (can start with different number for each author extracting data)   |  |
| <b>report_id</b>        | Report ID   |  |
| <b>reviewer</b>         | Review author name  |  |
| <b>title</b>            | Title   |  |
| <b>type</b>             | Type of literature  | article, report, website                                   |
| <b>source</b>           | How was the study found?  | electronic database, citation, hand search, website        |
| <b>language</b>         | Is the language English, Spanish, Portuguese, German, Dutch or French?  | English, Spanish, Portuguese, German, Dutch, French, other |
| <b>year1990_2015</b>    | Made between 1990-2015?   | yes, no  |
| <b>topic_relevance</b>  | Is the study aim to asses an intervention with the stigma-related outcome to improve societal attitudes, improve self-concept for people with TB, Improve behaviors of care givers? | general attitudes, self-concept, improve caregivers, other |
| <b>included</b>         | Does the study fit all the inclusion criteria?  | yes, no, unclear   |
| <b>exclusion_reason</b> | What was the reason for exclusion?  |  |
| <b>comments</b>         | Review authors comments   |  |

## SECOND ELIGIBILITY SCREEN

| Variable            | Explanation   | Answer categories                                |
|---------------------|---|--|
| <b>study_id</b>     | Individual study ID (can start with different number for each author extracting data) |  |
| <b>report_id</b>    | Report ID   |  |
| <b>reviewer</b>     | Review author name  |  |
| <b>title</b>        | Title   |  |
| <b>authors</b>      | Author/s  |  |
| <b>participants</b> | Is the study populations the general community, TB patients or care givers?           | general community, TB patient, care giver, other |

|                         |   |  |
|-------------------------|---|--|
| <b>method</b>           | Is the method for the intervention assessment experimental, quasi experimental, qualitative, mixed methods or review study? | RCT/ CRCT, [control for intragroup variance], quasi experimental [method for controlling bias/matching], mixed methods, qualitative, review study, other |
| <b>included</b>         | Does the study fit all the inclusion criteria?  | yes, no, unclear   |
| <b>exclusion_reason</b> | What was the reason for exclusion?  |  |
| <b>comments</b>         | Review authors comments   |  |

## Data abstraction

| Variable                    | Explanation  | Answer categories   |
|-----------------------------|--|---|
| <b>study_id</b>             | Individual study ID (can start with different number for each author extracting data)  |   |
| <b>report_id</b>            | Report ID  |   |
| <b>reviewer</b>             | Review author name   |   |
| <b>title</b>                | Title  |   |
| <b>authors</b>              | Author/s   |   |
| <b>year</b>                 | Year of publication  |   |
| <b>citcon</b>               | Citation and contact details   |   |
| <b>type</b>                 | Type of literature   | article, report, website  |
| <b>source</b>               | Electronic database, citation, hand search, website  |   |
| <b>language</b>             | Is the language English, Spanish, Portuguese, German, Dutch or French?   | English, Spanish, Portuguese, German, Dutch, French                         |
| <b>Intervention</b>         |  |   |
| <b>Intervention purpose</b> | Is the study outcome to Improve stigma related attitudes among the general community, improve self-concept for people with TB, Improve behaviors of care givers? | general attitudes, self-concept, improve caregivers (choose one or several) |
| <b>participants1</b>        | Is the study populations the general community, TB patients or care givers?  | general community, TB patient, care giver                                   |
| <b>stigma_participant1</b>  | Is this population assumed to be stigmatizing or being stigmatized?  | stigmatizing, stigmatized   |
| <b>stigma_type1</b>         | What type of stigma is the target for this population?   | anticipated, internalized, enacted  |
| <b>age1</b>                 | What age were the participants?  |   |
| <b>number1</b>              | Total number of this group of participants   |   |

|                              |  |  |
|------------------------------|--|--|
| <b>participants2</b>         | Does the study have a second population type?  | general community, TB patient, care giver  |
| <b>stigma_participant2</b>   | Is this population assumed to be stigmatizing or being stigmatized?  | stigmatizing, stigmatized  |
| <b>stigma_type2</b>          | What type of stigma is the target for this population?   | anticipated, internalized, enacted   |
| <b>age2</b>                  | What age were the participants?  |  |
| <b>number2</b>               | Total number of this group of participants   |  |
| <b>participants3</b>         | Does the study have a third population type?   | general community, TB patient, care giver  |
| <b>stigma_participant3</b>   | Is this population assumed to be stigmatizing or being stigmatized?  | stigmatizing, stigmatized  |
| <b>stigma_type3</b>          | What type of stigma is the target for this population?   | anticipated, internalized, enacted   |
| <b>age3</b>                  | What age were the participants?  |  |
| <b>number3</b>               | Total number of this group of participants   |  |
| <b>intervention_type</b>     | What type of intervention?   | information campaign, skill building, counselling, contact/interaction   |
| <b>specific_intervention</b> | Describe the intervention  |  |
| <b>BCT_type</b>              | What type of behavioral change technique did the intervention use?   | feedback and monitoring, social support, shaping knowledge, identity, natural consequences, self-belief  |
| <b>hiv</b>                   | Was the study targeting both HIV and TB stigma?  | hiv/tb, only tb  |
| <b>Methods</b>               |  |  |
| <b>study_design</b>          | RCT/ CRCT, [with query control for intragroup variance]/ quasi experimental [method for controlling bias/matching], mixed methods, qualitative, review study | experimental, [with query control for intragroup variance], quasi experimental [method for controlling bias/matching], mixed methods, qualitative, review study, other |
| <b>mixed_type</b>            | In the mixed-methods study, was the outcome of interest in the quantitative or qualitative module (or both)?   | quantitative, qualitative, both  |
| <b>quant_type</b>            | What type of quantitative study?   | RCT, CRT, longitudinal, cross-sectional  |
| <b>qual_type</b>             | What type of qualitative study?  | phenomenology, ground theory, ethnography, action research, descriptive study  |
| <b>review_type</b>           | What type of review study?   | descriptive, meta study  |
| <b>duration</b>              | Total study duration (months)  |  |
| <b>Grading</b>               |  |  |
| <b>cochrane_grade</b>        | Cochrane GRADE for RCT's (1-4)   | Very low confidence, Low confidence, Moderate confidence, High confidence  |
| <b>nawcasatle_ottawa</b>     | Newcastle Ottawa for non-randomized trials (1-4)   | Very low confidence, Low confidence, Moderate confidence, High confidence  |

|                                |  |   |
|--------------------------------|--|---|
| <b>spencer_framework</b>       | Spencer's framework for assessing qualitative individual studies   |   |
| <b>grade_cerqual</b>           | Confidence in findings from qualitative evidence synthesis   | Very low confidence, Low confidence, Moderate confidence, High confidence |
| <b>Outcomes</b>                |  |   |
| <b>anticipated_outcome</b>     | Outcome definition anticipated stigma  |   |
| <b>internal_outcome</b>        | Outcome definition internalized stigma   |   |
| <b>enacted_outcome</b>         | Outcome definition enacted stigma  |   |
| <b>unit_anticipated</b>        | Unit of measurement, anticipated stigma  |   |
| <b>unit_internal</b>           | Unit of measurement, internalized stigma   |   |
| <b>unit_enacted</b>            | Unit of measurement, enacted stigma  |   |
| <b>scale_range</b>             | For scales: upper and lower limits, and whether high or low score is good  |   |
| <b>scale_valid</b>             | For scales: if validated   | yes, no   |
| <b>Result</b>                  |  |   |
| <b>Anticipated stigma (a)</b>  |  |   |
| <b>n_group_a</b>               | Number of participants allocated to each intervention group  |   |
| <b>n_a</b>                     | Sample size  |   |
| <b>missing_a</b>               | Missing participants   |   |
| <b>result_summary_a</b>        | Summary data for each intervention group (e.g. 2×2 table for dichotomous data; means and SDs for continuous data, summarizing matrix or other from qualitative data) |   |
| <b>effect_a</b>                | Estimate of effect with confidence interval; P value. Increase/decrease in stigma for qualitative reviews  |   |
| <b>Internalized stigma (i)</b> |  |   |
| <b>n_group_i</b>               | Number of participants allocated to each intervention group  |   |
| <b>n_i</b>                     | Sample size  |   |
| <b>missing_i</b>               | Missing participants   |   |
| <b>result_summary_i</b>        | Summary data for each intervention group (e.g. 2×2 table for dichotomous data; means and SDs for continuous data, summarizing matrix or other from qualitative data) |   |
| <b>effect_i</b>                | Estimate of effect with confidence interval; P value. Increase/decrease in stigma for qualitative reviews  |   |
| <b>Enacted stigma (e)</b>      |  |   |

|                         |  |                 |
|-------------------------|--|-----------------|
| <b>n_group_e</b>        | Number of participants allocated to each intervention group  | n_group2        |
| <b>n_e</b>              | Sample size  | n2              |
| <b>missing_e</b>        | Missing participants   | missing2        |
| <b>result_summary_e</b> | Summary data for each intervention group (e.g. 2×2 table for dichotomous data; means and SDs for continuous data, summarizing matrix or other from qualitative data) | result_summary2 |
| <b>effect_i</b>         | Estimate of effect with confidence interval; P value. Increase/decrease in stigma for qualitative reviews  |                 |
| <b>Miscellaneous</b>    |  |                 |
| <b>funding_source</b>   | Funding source   |                 |
| <b>references</b>       | References to other relevant studies   |                 |
| <b>correspondence</b>   | Correspondence required  |                 |
| <b>comments_author</b>  | Comments by the review authors   |                 |

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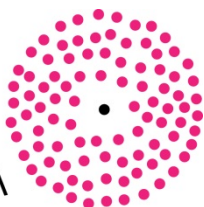


## The TB Stigma Measurement Challenge

### Expert Consultation

#### The Hague, Netherlands

TB STIGMA  
MEASUREMENT

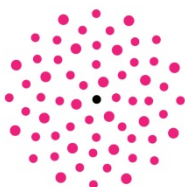


We know that perceptions about the way a person may be treated in a health care interaction strongly influence the timing, location, and quality of health seeking. We all agree that discrediting persons with TB is wrong and counterproductive to TB care because stigmatizing behavior has a negative impact on adherence and recovery.

TB STIGMA  
MEASUREMENT



TB STIGMA  
MEASUREMENT



#### The TB Stigma Measurement Challenge

A validated TB stigma scale that is cross-culturally robust could help to track global progress in reframing TB and could assist to identify effective interventions to reduce shame, discrimination and fear of mistreatment.

TB STIGMA  
MEASUREMENT



However, there are many questions as to whether such a measure is possible. TB

stigma is not a universal social fact (as it is often imagined) but rather a culturally constructed and potentially dynamic construct. Indeed some studies suggest that an identical behavior can be experienced as more or less stigmatizing depending on the characteristics of the person . So TB stigma may not be measurable with a uniform questionnaire. It may be yet another instance where an intersectional approach to multiple forms of difference

(prejudice based upon race, gender, class, co-morbidities, sexualities) may be required.

KNCV Tuberculosis Foundation, together with academic and policy partners, will convene an expert consultation to unpack TB stigma measurement scales. The consultation will present preliminary results of 7 new studies, and serve as a technical forum to debate current and future tools.

The agenda is under development, but the main questions to be tackled include:

### **What do TB stigma scales actually measure?**

We recognize that many TB patients are managing multiple identities that are stigmatized. This makes measurement additionally challenging. By asking vague close-ended questions about discrimination, one risks conflating many different types of prejudice.

We know that when providers lack cultural competence with a wide array of TB patient groups their contact investigations are of lower quality and effectiveness. We observe this with treatment adherence and outcomes as well.

- *Is TB stigma indivisible from HIV stigma?*
- *How do TB stigmas relate to stigmas of poverty, incarceration and/or substance use?*
- *What do the validation studies tell us about the utility of TB stigma scales?*
- *Are TB stigmas essentially compound stigmas?*

### **What does the presence of anticipated, internalized, and enacted TB stigma mean for behavior?**

Even when there is agreement on TB stigma as a concept, there is not always a linear or predictable consequence on behavior. Indeed in at least some TB stigma studies shame associated with TB actually increased timeliness of case seeking.

- *Do higher rates of anticipated TB stigma in the general population correlate with lower health care seeking for TB symptoms?*
- *Do higher rates of enacted TB stigma in health care settings led to reduced TB screening or lower rates of TB testing?*

- *How do we understand settings with high measured levels of TB stigma but also high levels of TB care seeking, treatment adherence, good outcomes?*

### **How important is measuring TB stigmas?**

Given the measurement challenges, is it really TB stigma we want to track and measure? Or are we better off tracking something easier like the cultural competence of TB health care providers to work effectively with stigmatized communities?

- *How important is reducing TB stigma for TB patients? Is it a top priority?*

### **Are TB stigmas susceptible to intervention?**

We know from the HIV world that HIV stigma has morphed quite a bit with policy, treatment and societal shifts. We are less sure of how TB stigmas are evolving over time. Once TB stigma can be reliably measured, our lack of understanding of TB stigma reduction strategies will be the next hurdle.

- *Is correct knowledge of TB transmission or curability associated with lower TB stigma? Can educational interventions work?*
- *Are TB stigmas dynamic over time and how can these dynamics be explained?*
- *What are the evidence-based approaches to reduce TB stigmas?*

### **Logistics**

The meeting will take place over two days (February 11<sup>th</sup> and 12<sup>th</sup>) in The Hague, Netherlands.

### **Program**

The 2-day program is under development. Current plans include: seven scientific presentations of new research on TB stigma measurement, small technical discussions of key measurement questions, production of a TB stigma measurement research agenda. We are exploring the potential for proceedings to form a special issue of a peer review journal.

### **Invitations**

Formal invitations for 10 TB stigma measurement experts will be sent via email in late January.

General invitations for the scientific presentations will sent to a wider audience in early February, 2016.